



# EXAMINING RURAL CANCER PREVENTION AND CONTROL EFFORTS

POLICY BRIEF AND RECOMMENDATIONS TO THE SECRETARY

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AUGUST 2019

**NACRHHS**

National Advisory Committee on Rural Health and Human Services

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**EDITORIAL NOTE**

During its 85th meeting in Sacramento, California, the National Advisory Committee on Rural Health and Human Services (hereinafter referred to as “the Committee”) examined rural cancer control<sup>i</sup> as one of two topics—the second topic focused on supportive services and caregiving for older rural Americans. Throughout the course of the meeting, the Committee heard from subject matter experts on rural cancer control efforts at the national and state levels. As part of the Committee’s meeting, members traveled to Willows, California and visited Northern Valley Indian Health, Inc. There, members heard from clinic staff about services to surrounding tribal and non-tribal communities, and had a broader discussion about challenges and opportunities to improve cancer care in the community. Underlying these conversations, the Committee sought to understand the full continuum of cancer care—from prevention to survivorship—among rural and underserved populations.

**ACKNOWLEDGEMENTS**

The Committee acknowledges all those whose participation helped make the April 2019 convening in Sacramento, the adjoining site visit in Willows, and this policy brief possible.

The Committee expresses its gratitude to each of the presenters for their contributions to the meeting and for their subject matter expertise. These individuals are: Nikki Hayes, MPH (National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Prevention and Control); Shobha Srinivasan, PhD (National Cancer Institute, National Institutes of Health); Rosemary Cress, MPH, DrPH (Cancer Registry of Greater California and UC Davis School of Medicine); Moon Chen, Jr., MPH, PhD (UC Davis School of Medicine and UC Davis Comprehensive Cancer Center); and John Roachat, MD (Mendocino Coast District Hospital).

The Committee thanks Chester Austin, Inder Wadhwa, and the staff at the Willows clinic of Northern Valley Indian Health, Inc. for hosting the Rural Cancer Prevention and Control site visit.

Lastly, the Committee extends its gratitude and appreciation to Alfred Delena for coordinating the activities of this meeting, summarizing the Committee’s findings, and contributing to this policy brief.

<sup>i</sup> According to the [National Cancer Institute](#), *cancer control* refers to “the conduct of basic and applied research in the behavioral, social, and population sciences to create or enhance interventions that, independently or in combination with biomedical approaches, reduce cancer risk, incidence, morbidity and mortality, and improve quality of life.”

## POLICY RECOMMENDATIONS

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**Recommendation 1:** The Committee recommends the Secretary support combined funding from the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and the National Cancer Institute to develop, implement, and evaluate a rural patient navigation program to enhance care coordination, particularly in tribal communities and persistent poverty counties.

**Recommendation 2:** The Committee recommends the Secretary work with Congress to increase funding to expand the National Cancer Institute's Rural Cancer Control Program and partnerships with rural and tribal providers in implementing cancer control projects.

**Recommendation 3:** The Committee recommends the Secretary and the Department of Health and Human Services implement a national educational campaign to promote cancer-related clinical information and resources supported by the Department to improve the delivery of cancer care for providers and clinicians practicing in rural and underserved areas.

**Recommendation 4:** The Committee recommends the Centers for Medicare & Medicaid Services conduct more targeted outreach for rural providers on how to use existing Medicare codes (e.g., chronic care management) for cancer care coordination.

**Recommendation 5:** The Committee recommends the Centers for Disease Control and Prevention require states, territories, and tribes or tribal organizations to assess rural-urban cancer mortality rates as part of their cancer control plans and, where appropriate, develop and implement rural-focused cancer control goals, objectives, or strategies, particularly in areas with high rural cancer mortality rates.

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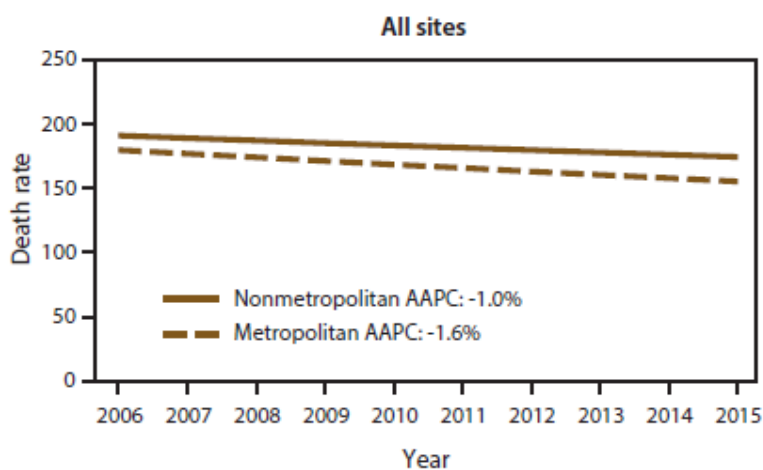
## INTRODUCTION

Cancer is the second leading cause of death in the United States. In 2016, 1.65 million new cases of cancer were reported and close to 600,000 Americans died of cancer.<sup>1</sup> Cancers of the breast, the lung, and the colon and the rectum in females and cancers of the prostate, the lung, and the colon and the rectum in males contributed to the greatest number of cancer mortality cases.<sup>1</sup> Nationally, the trends in cancer incidence has varied by sex; whereas the overall cancer incidence among males declined roughly 2 percent per year in the past decade, overall incidence among females has remained relatively stable.<sup>2</sup> However, age-adjusted cancer death rates (per 100,000 population) for both males and females have been on a downward trend—reaching a high of 215.1 deaths<sup>2</sup> in 1991 down to 152.5 deaths<sup>3</sup> in 2017. Despite this continued decline in national cancer mortality, research demonstrates a distinct disparity in cancer mortality between rural and urban populations.<sup>4,5,6,7</sup>

## BACKGROUND

### Rural Cancer

Compared to metropolitan (urban) areas, nonmetropolitan (rural) counties had lower average annual age-adjusted cancer incidence rates for all cancer sites<sup>ii</sup> combined, but higher mortality rates.<sup>4</sup> Death rates for all cancer sites combined were slow to decrease in rural counties, further widening the gap (see **Figure 1**). Researchers also noted higher incidence and mortality rates among rural regions for certain preventable cancers, specifically, lung, laryngeal, colorectal, and cervical cancers.<sup>4</sup> Moreover, a 2011 study published in the *Journal of Cancer Epidemiology* further demonstrates the geographic disparity in mortality rates. In their analysis, researchers reported an 8 percent higher all-cancer mortality and an 18-20 percent higher lung cancer mortality for rural residents compared to their urban counterparts.<sup>5</sup>



**Figure 1:** Trends in annual age-adjusted death rates among persons of all ages for common cancers in nonmetropolitan and metropolitan counties, by year of death—United States, 2006-2015. Abbreviation: AAPC (average annual percent change).<sup>4</sup>

The disparity in death rates between rural and non-rural counties is attributable to several contributing factors. In general, rural populations experience higher rates of poverty, have less access to health care

<sup>ii</sup> *Cancer site* refers to the area of the body in which the cancer originates (e.g., the lung, the breast, the prostate).

services and transportation, and are more dependent on public health insurance programs such as Medicare and/or Medicaid.<sup>8, 9, 10</sup> Specifically, rural Americans are more likely to engage in cancer-causing risk behaviors,<sup>iii</sup> namely cigarette smoking and physical inactivity.<sup>11, 12</sup> Moreover, disparities in socioeconomic indicators<sup>iv</sup> may have an even greater impact on and explain the relationship between the rural-urban continuum and all-cancer mortality, suggesting that differences in cancer mortality are independently associated with both the rural-urban continuum and socioeconomic deprivation.<sup>5</sup> Not specific to rurality, but related to socioeconomic deprivation, additional evidence has shown relationships between poverty and cancer site-specific incidence, especially between higher poverty and certain cancers (e.g., HPV- and tobacco-related cancers).<sup>13</sup> Higher neighborhood poverty and higher social isolation have also been associated with an increased risk of cancer death.<sup>14</sup>

Given the confluence of these challenges, the Committee is concerned about the underlying factors that affect a rural patient's ability to access critical health care services to prevent and detect cancer, or to fully engage in a comprehensive cancer treatment plan once the cancer has been diagnosed.

### Barriers to Accessing to Cancer Care

Populations in isolated small towns, farms, frontiers, and Indian reservations generally have less direct access to health services due primarily to a disparity in the supply of the health workforce. As a 2014 analysis revealed, a significantly higher number of primary care physicians worked in an urban location (53.3 per 100,000 population) compared to a rural area (39.8 per 100,000 population).<sup>15</sup> Moreover, physician turnover tends to be higher for counties that lack a hospital, have a small population, and a low supply of primary care physicians, which make it further challenging for workforce recruitment and retention.<sup>16</sup> Among specialists, the workforce disparity is even greater. In general, there are roughly 30 specialists per 100,000 people practicing in rural communities compared to 263 specialists per 100,000 urban residents.<sup>v</sup> Among cancer care specialists, from its 2018 Practice Census Survey, the American Society of Clinical Oncology reports 7 percent of oncologists practice in a rural location.<sup>17</sup>

Because of limited access to a primary care physician or any type of specialist, rural residents often travel longer distances to receive care. In one study, researchers observed an association between rurality and median travel times to various cancer care institutions.<sup>18</sup> Specifically, those living in small towns and isolated rural areas traveled, on average, 180 minutes, 105 minutes, or 59 minutes to access services at an NCI-designated Cancer Center, an academic-based center, or any specialized care center, respectively. By comparison, urban patients traveled, on average, 57 minutes, 22 minutes, or 11 minutes, respectively, to receive cancer care. In another study, the median distance older rural patients seeking colorectal cancer services traveled from their place of residence to see urban-based specialists varied between 47.8 and 67 miles.<sup>19</sup> Researchers further reported that 30 percent of patients from isolated small rural areas had access to a medical oncologist that was within 30 miles of their place of residence; 27.4 percent had access

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<sup>iii</sup> The prevalence of health risk behaviors that increase the likelihood of cancer can be prevented. One estimate projected that [42 percent of all cancers in adults, ages 30 and over, were potentially avoidable](#)—this included 19 percent of all cancers caused by cigarette smoking, 7.8 percent from excess body weight, 5.6 percent from alcohol consumption, 4.7 percent from ultraviolet radiation, and 2.9 percent from physical inactivity.

<sup>iv</sup> As noted in Singh, et al. 2011, researchers used “11 census-based social indicators” that included, among others, education, unemployment, income, housing quality, and poverty. Singh and colleagues used the term *socioeconomic deprivation* to describe disparities in these social indicators; all U.S. counties were categorized into 10 groups, ranging from the most deprived to the least deprived.<sup>5</sup>

<sup>v</sup> Figures on specialists practicing in rural and urban areas is provided by the National Rural Health Association. (Webpage). Accessed at <https://www.ruralhealthweb.org/about-nrha/about-rural-health-care>.

to a radiation oncologist within the same distance. By contrast, urban patients had greater access, 99.6 percent to a medical oncologist and 98.4 percent to a radiation oncologist.

Longer travel distances to health services also affects cancer screening and participation in clinical trials. Compared to urban populations, low screening rates have been observed among rural residents in different settings;<sup>20</sup> for examples, breast and colorectal screenings among Medicare beneficiaries, breast and cervical screenings among Hispanic and American Indian women residing in the American Southwest, and cervical screenings among women living in persistent poverty rural counties.<sup>21,22,23</sup> A primary barrier that may explain, in part, lower screening rates stems from a lack of a physician recommendation to receive a screening.<sup>20</sup> In one study, among Federally Qualified Health Center (FQHC) patients, rural participants were significantly less likely than urban participants to have received a physician recommendation to get screened, received any information on fecal occult blood tests (FOBTs),<sup>vi</sup> or completed an FOBT.<sup>20</sup> Yet rural patients in the study were more likely to report knowing the benefits of using FOBT to detect colorectal cancer. This difference in physician recommendation might come from a lack of access to information—rural providers may not be well informed about screening guidelines and cost-effective tests such as FOBT.<sup>20</sup>

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***While access to clinical trials for rural patients is challenging, evidence demonstrates that when rural cancer patients do receive the same quality of care as their urban counterparts, identical survival rates for nearly all cancer sites can be achieved, thus, closing the gap in cancer outcomes between rural and non-rural patients.<sup>24</sup>***

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Geographic differences may also limit one's ability to participate in a clinical trial. For instance, a report of trial enrollment across North Carolina showed low enrollment rates for a majority of rural counties—this finding was consistent with prior years.<sup>25</sup> Moreover, socioeconomic status plays a role in limiting or enabling access and participation. As one study shows, cancer patients with higher incomes that lived in areas with a higher

number of cancer specialists had a greater likelihood of enrolling in clinical trials.<sup>26</sup> While access to clinical trials for rural patients is challenging, evidence<sup>vii</sup> demonstrates that when rural cancer patients do receive the same quality of care as their urban counterparts, identical survival rates for nearly all cancer sites can be achieved, thus, closing the gap in cancer outcomes between rural and non-rural patients.<sup>24</sup> This research further suggests that improving access to quality cancer treatment may reduce cancer disparities and improve survivorship for rural and urban patients.

In all, despite an overall national decrease in cancer mortality rates, rural-urban differences in outcomes persist. These gaps may be explained by additional rural-urban disparities in cancer-causing risk factors, the supply of primary care physicians, oncologists, and other cancer care specialists, and the distance a patient has to travel to reach health facilities to receive care.

## FEDERAL PROGRAMS

Across the U.S. Department of Health and Human Services (HHS), there are several key agencies that administer programs which support and enhance national and rural cancer control efforts. These agencies include the National Cancer Institute (NCI) at the National Institutes of Health (NIH), the Centers for

<sup>vi</sup> FOBTs are “the most feasible and cost-effective screening option for low-income, underinsured populations.”<sup>20</sup>

<sup>vii</sup> Researchers analyzed data from patient medical records for participants who enrolled in clinical trials from 1986 to 2012.

Disease Control and Prevention (CDC), the Centers for Medicare & Medicaid Services (CMS), and the Health Resources and Services Administration (HRSA). Additional federal agencies that can address cancer care for rural patients include the Agency for Healthcare Research and Quality (AHRQ), through its work on clinical guidelines and health systems assessment, and the Indian Health Service (IHS), through the administration of clinical and preventive services in tribal health facilities.



**Figure 2:** Rural Cancer Control Supplements grants awarded to 21 NCI-designated Cancer Centers in the United States in 2018. Sources: [NCI's Rural Cancer Control Program](#) and [Rural Supplements to NCI-Designated Cancer Centers Abstracts](#)

## NCI Programs

Located within the NIH, NCI serves as the lead federal agency devoted to conducting and progressing cancer research for the nation by leveraging its extensive infrastructure to understand the underpinnings of cancer and to address the full continuum of cancer control. Through its portfolio, NCI oversees and administers investigator-initiated research grants, advances the nation's [cancer surveillance activities](#), conducts [clinical trials](#), selects and funds [NCI-designated Cancer Centers](#), and funds a range of other cancer research programs including the [NCI Community Oncology Research Program \(NCORP\)](#). These programs are critical to reducing the cancer burden for the nation and especially among rural and underserved communities.

In the past, NCI has supported some projects and activities to improve rural and minority health. For instance, in 2011, NCI and partner Institutes at the NIH launched the [Intervention Research to Improve Native American Health \(IRINAH\)](#) program. The purpose of IRINAH is for researchers and their partners to design and evaluate the effectiveness of interventions for Native and Indigenous communities that promote health and prevent disease with a long-term goal of reducing morbidity and mortality. However, recognizing that only 3 percent of NCI's portfolio was dedicated to rural and even a smaller portion for



Native populations, NCI's Division of Cancer Control & Population Sciences (DCCPS) initiated and participated in a series of events with the CDC, HRSA's Federal Office of Rural Health Policy (FORHP), and the National Rural Health Association. The intent was to learn more about rural disparities. Recognizing the high rural mortality rates, NCI's leadership decided to focus more attention on rural cancer control. In 2018, NCI awarded supplemental funding to 21 NCI-designated Cancer Centers to strengthen research capacity and foster partnerships between the Cancer Centers and rural health facilities (HRSA-funded FQHCs and IHS clinics); 9 of the 21 Cancer Centers have a specific focus on Native populations (see **Figure 2** and see **Appendix A** to read more about the Committee's site visit to one of the nine). NCI, in partnership with HRSA, also co-funded the South Carolina Rural and Minority Health Research Center to understand the needs and capacity of rural hospitals and clinics, develop referral guidelines for cancer care, and improve follow-up and survivorships. In 2019, NCI announced additional funding for the continuation of the rural supplements to Cancer Centers and a new program: [Improving the Reach and Quality of Cancer Care in Rural Populations](#).

### CDC Programs

As the nation's public health agency, the CDC conducts critical scientific research and provides health information to safeguard the public from disease and other health threats. Within the CDC, the Division of Cancer Prevention and Control (DCPC) is the primary unit that focuses on advancing cancer prevention. [DCPC's National Cancer Programs](#) enables the CDC to work with state health agencies, tribes and tribal entities, and other organizations to develop, implement, and promote effective cancer prevention and control practices. Specifically, the National Cancer Programs portfolio supports significant national cancer surveillance, state cancer control plans, and screening services.

The [National Program of Cancer Registries \(NPCR\)](#) works in conjunction with NCI's Surveillance, Epidemiology, and End Results (SEER) Program to collect and disseminate data for the entire U.S.

### Case Study: Public-Private Collaboration to Advance Cancer Care in Rural Appalachia

Analogous to national trends, cancer is a leading cause of death in the Appalachian Region and similarly, rural-urban differences in cancer mortality have been documented.<sup>27, 28</sup> A 2017 study published in the *Journal of Rural Health* reported a 15 percent higher age-adjusted death rate for rural Appalachian counties (195.2 deaths per 100,000 people) compared to urban non-Appalachian areas (170.2 deaths per 100,000 people) from 2007-2011.<sup>28</sup> During that same time frame, rural Appalachians living in Kentucky, West Virginia, Alabama, Tennessee, and Mississippi experienced 17-36 percent higher mortality rates than the rest of the country.<sup>28</sup>

In response to these growing geographic and region-specific disparities in cancer outcomes, a public-private partnership was established. In 2017, NCI and the Federal Communications Commission (FCC), in collaboration with other partners, introduced the [Linking & Amplifying User-Centered Networks through Connected Health \(LAUNCH\)](#) initiative. The project aims to improve cancer care, specifically symptom management support, for rural patients in Appalachia by an expanding broadband access. An [initial analysis](#) of both cancer mortality and broadband data revealed that rural areas with the highest cancer mortality burden also faced considerable gaps in accessing broadband. Along with NCI and FCC's Connect2Health Task Force, additional partners engaged in LAUNCH include the NCI-designated University of Kentucky Markey Cancer Center, the University of San Diego's Design Lab, which brings a "people-centered thinking" approach to address cancer symptom management, and Amgen, a biotechnology company that has been working in oncology for more than 30 years.

As of the writing of this brief, LAUNCH is in the early stages of implementing the demonstration. If successful, LAUNCH could serve as a promising model to help other rural areas and populations similarly affected.

population. Data collected by the NPCR can help researchers, policymakers, and other stakeholders monitor the disease burden, identify certain populations that are at an increased risk (e.g., rural and tribal), and assess additional needs for prevention. Additionally, data collected can serve as the backbone for the development of reports (e.g. [the Annual Report to the Nation](#)) and strategic cancer control programming. The funding, guidance, and technical assistance to states, territories, and tribes or tribal organizations to design and implement strategic, sustainable cancer control plans is overseen by the [National Comprehensive Cancer Control Program \(NCCCP\)](#). These plans can bring greater attention and awareness to the challenges faced by rural communities. Whereas the NCCCP and the NPCR fund cancer control and national surveillance activities, the CDC's [Colorectal Cancer Control Program \(CRCCP\)](#) and the [National Breast and Cervical Cancer Early Detection Program \(NBCCEDP\)](#) support cancer screening for age-appropriate, underserved men and women. The CRCCP works with health systems, such as FQHCs, to implement evidence-based interventions to increase screening rates in clinics they support. The NBCCEDP provides breast and cervical cancer screenings and diagnostic follow-up for low-income, uninsured, and underserved women in need of these services.

In addition to the National Cancer Programs, the CDC also manages [three national awareness campaigns](#) that educate people on cancer symptoms and the importance of screening. Lastly, the CDC supports other initiatives that focus on cancer prevention, education, and research, namely through its [Cancer Genomics Program](#), the [National Tobacco Control Program](#), and the [Cancer Prevention and Control Research Network \(CPCRN\)](#),<sup>viii</sup> which represents a network within the [Prevention Research Centers](#). Each of these programs have the potential to improve and increase prevention efforts in and among rural and underserved communities.

### **CMS Programs**

As a payer of health care services for Medicare and Medicaid beneficiaries, CMS plays an important role in covering cancer care through standard benefits. [Medicare Part A and Part B](#) covers medically-necessary services and treatments to beneficiaries that includes, among others, inpatient hospital stays, home health, hospice care, outpatient surgeries, and chemotherapy drugs and radiation treatments administered in an outpatient clinic. [Medicare Part B](#) covers some preventive services, such as smoking cessation and screenings for cancers of the breast, colorectum, cervix, lung, and prostate. Beneficiaries that are covered by Medicare Part A and/or Part B are eligible to enroll in a prescription drug plan under [Medicare Part D](#) that helps lower the cost of prescription drugs. Under Medicaid, benefits provided include some preventive services such as smoking cessation and screening. [Medicaid's Early and Periodic Screening, Diagnostic, and Treatment](#) benefit provides comprehensive services to young people under age 21 that includes appropriate immunizations (as recommended by [CDC's Advisory Committee on Immunization Practices](#)) and health education.

In addition, [CMS reimburses for chronic care management services](#) through the Physician Fee Schedule, tests payment models to improve the effectiveness and efficiency of specialty care, including oncology,<sup>ix</sup> and establishes a [core set of quality measures to monitor quality of care](#) provided to adult Medicaid enrollees.

<sup>viii</sup> The [CPCRN is co-funded by CDC and NCI](#).

<sup>ix</sup> In 2016, CMS' Innovation Center initiated the [Oncology Care Model \(OCM\)](#), a five-year, physician-led, multi-payer demonstration designed to promote high-quality coordinated cancer care. Through the OCM, participating physician practices enter into "payment arrangements that include financial and performance accountability for episodes of care surrounding chemotherapy administration to cancer patients."

## HRSA Programs

With the goal of increasing access to quality health care services for geographically, economically or medically underserved populations nationwide, HRSA supports funding, training, technical assistance, and research initiatives to address a variety of issues that affect primary care, rural health, workforce development, maternal and child health, and HIV/AIDS. Although HRSA's programs do not specifically target cancer-related activities, opportunities to increase screenings and improve treatment for rural and underserved patients can be addressed through the Health Center Program, the 340B Drug Pricing Program, community-based rural programs, and telehealth grants.

[HRSA-funded health centers](#) provide comprehensive primary care to over 27 million people; of which roughly 1 in 5 are rural residents. FQHCs focus heavily on preventive services, which includes cancer screenings. Additionally, the [340B Drug Pricing Program](#) helps make expensive cancer treatment drugs more accessible to low-income and at-risk populations; the program provides assistance to eligible entities such as FQHCs and Critical Access Hospitals (CAHs). Lastly, under Section 330A of the Public Service Act, FORHP administers several [community-based rural pilot programs](#), of which grantees may focus their activities on cancer prevention and care coordination. FORHP also oversees funding for [telehealth networks](#), which can play a pivotal role in addressing the disparity in the supply of rural oncologists, circumventing long distances to comprehensive cancer care centers, and improving care coordination for rural cancer patients. One prominent example of telehealth in practice is the University of Kansas Medical Center's successful implementation of a teleoncology program.<sup>29</sup>

Of note, FORHP and HRSA have a track record of partnering with HHS agencies, namely the CDC<sup>x</sup> and certain institutes at NIH,<sup>xi</sup> to create opportunities for more targeted efforts to improve rural health.

## POLICY RECOMMENDATIONS

The Committee acknowledges that comprehensive, strategic approaches are needed to address the magnitude of the multiple intersecting access-to-care barriers that limit rural cancer patients from engaging in the full continuum of care. In an attempt to tackle these barriers and to ultimately reduce rural cancer mortality disparities, the Committee presents its recommendations, which focus on enhancing federal funding to increase and improve rural cancer control programming, educating rural providers on clinical information and billing for care coordination, and elevating awareness of rural cancer disparities in comprehensive cancer control plans for states, territories, and tribes or tribal organizations. These recommendations were informed by subject matter experts and stakeholders during the Committee's April 2019 meeting in Sacramento and the subcommittee's site visit to Willows, California.

### Enhance Federal Funding to Increase and Improve Rural Cancer Control Activities

At its site visit in Northern Valley Indian Health (NVIH) in Willows, CA, the Committee consistently heard about the need for better communication between rural providers and specialists. NVIH staff and

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<sup>x</sup> In 2017, the CDC collaborated with HRSA to develop and disseminate its [Morbidity and Mortality Weekly Reports](#) spotlighting rural disparities on several key health and safety issues.

<sup>xi</sup> As documented in the Committee's [policy brief on addressing the burden of rural COPD](#), beginning in 2016, the National Heart, Lung and Blood Institute (NHLBI) at the NIH partnered with the CDC, HRSA and other federal agencies to host town halls as part of developing the congressionally-mandated *COPD National Action Plan*. Following the Action Plan's release in May 2017, [NHLBI convened a group of COPD and rural health experts](#) to discuss how the Action Plan can be specifically implemented to address the needs of rural communities. As a follow-up, FORHP hosted another gathering that focused on establishing rural-specific, action-oriented commitments to implement the goals of the Action Plan.

stakeholders emphasized the important role that patient navigators can play to bridge those communication challenges and strengthen care coordination for rural patients. Yet issues of defining cancer patient navigation and differentiating patient navigators from other public health workers such as community health workers (CHWs) and [Community Health Representatives \(CHRs\)](#) surfaced.<sup>xii</sup>

In the context of cancer care, patient navigation<sup>xiii</sup> refers to “individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality health and psychosocial care from pre-diagnosis through all phases of the cancer experience.”<sup>30</sup> Research on cancer patient navigation programs—similar to CHWs<sup>31,32</sup>—have been shown to be effective in addressing barriers and improving access to care across the cancer continuum.<sup>33,34,35</sup> However, much like CHWs, patient navigators rely on several sources of public and private funding that may not be sustainable for the long-term.<sup>30</sup> Given the growing interest and promise in patient navigators and other frontline public health workers, the Committee encourages HHS agencies to invest in them as well as find ways to sustainably integrate them into the current healthcare infrastructure. For the purposes of this recommendation, the Committee believes developing a national rural cancer care coordination program with braided funding from the CDC, HRSA, and NCI can improve prevention and decrease mortality for rural and underserved communities. Moreover, this program should include various frontline public health workers (e.g., navigators, CHWs, CHRs, etc.) to work in tandem with rural health providers and specialists.

**Recommendation 1:** The Committee recommends the Secretary support combined funding from the CDC, HRSA, and NCI to develop, implement, and evaluate a rural patient navigation program to enhance care coordination, particularly in tribal communities and persistent poverty counties.<sup>xiv</sup>

Additionally, the Committee commends the innovative and collaborative work of NCI and believes NCI should continue building upon its efforts to advance rural cancer control by expanding its reach to further strengthen and improve partnerships with local health clinics.

**Recommendation 2:** The Committee recommends the Secretary work with Congress to increase funding to expand NCI’s Rural Cancer Control Program and partnerships with rural and tribal providers in implementing cancer control projects.

### **Educate Rural Health Care Providers on Clinical Resources & Billing for Care Coordination**

Similar to the HHS education and outreach campaign to health professionals in rural and underserved areas on chronic care management (CCM),<sup>xv</sup> the Committee believes a national awareness campaign to

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<sup>xii</sup> While patient navigators, CHWs, and CHRs all have distinct roles, these *navigators* “share core responsibilities that include providing resources, social support, informational counseling, patient advocacy, and outreach to vulnerable populations.”<sup>30</sup>

<sup>xiii</sup> This definition of *patient navigation*, with respect to cancer care, is defined by the Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers.<sup>30</sup>

<sup>xiv</sup> This recommendation aligns with a recommendation outlined in Osundina, Garfield, and Downer (2013) that reads: “payers and policy makers should continue to provide short-term funding opportunities (i.e., grants) for patient navigation programs.”<sup>30</sup>

<sup>xv</sup> As required under Section 103 of the [Medicare Access and CHIP Reauthorization Act of 2015 \(MACRA; P.L. 114-10\)](#), the CCM campaign was conducted by FORHP and CMS’ Office of Minority Health.

educate rural providers on clinical information and resources is paramount. During the meeting, Committee members heard from a practicing rural oncologist who spoke about the lack of access to new evidence from the clinical literature. This national campaign—which is comparable to a prior recommendation on COPD<sup>36</sup>—would provide relevant clinical information and resources to providers practicing in rural areas to enhance cancer care. Moreover, this campaign would serve to decrease existing rural cancer disparities, as outlined in this brief, which may encourage innovative public-private partnerships to reduce the disease burden. The Committee encourages the Secretary to include the NCI, AHRQ, CMS, CDC, HRSA, and IHS in the campaign’s development and implementation. Lastly, as part of this effort, the Committee believes the [National Network of Libraries of Medicine](#) should be involved as its goal is to “... improve public health by providing U.S. health professionals with equal access to biomedical information and improving individuals' access to information to enable them to make informed decisions about their health.”

**Recommendation 3:** The Committee recommends the Secretary and HHS implement a national educational campaign to promote cancer-related clinical information and resources supported by the Department to improve the delivery of cancer care for providers and clinicians practicing in rural and underserved areas.

Along with the aforementioned national campaign, the Committee sees value in HHS, specifically CMS, revisiting the previous FORHP- and CMS-led CCM campaign and conducting specific outreach to inform rural providers on how to use existing Medicare codes to bill for care coordination. As referenced earlier, under the current Physician Fee Schedule, Medicare reimburses for CCM services furnished to Medicare beneficiaries with two or more chronic conditions. The Committee believes rural providers should have the relevant information on how to accurately bill for services to better support cancer care coordination.

**Recommendation 4:** The Committee recommends CMS conduct more targeted outreach for rural providers on how to use existing Medicare codes (e.g. CCM) for cancer care coordination.

### **Elevate Awareness of Rural Cancer Disparities in Comprehensive Cancer Control Plans**

As mentioned earlier, the CDC’s National Comprehensive Cancer Control Program (NCCCCP) oversees the development and implementation of [strategic, coalition-driven, sustainable cancer control plans](#) that assess the burden of cancer in jurisdictions, emphasize primary prevention and treatment activities, and leverage resources to implement strategies at the local and state levels. As of 2019, the CDC currently supports coalitions in all 50 states, the District of Columbia, 6 U.S. Associated Pacific Islands and Puerto Rico, and 8 tribes or tribal organizations. The coalitions are strengthened by the [Comprehensive Cancer Control National Partnership \(CCNPP\)](#), a group of leading national cancer organizations and federal partners, which include the CDC, HRSA, and NCI.

Since NCCCCP grantees are not required to report the geographic population makeup of their jurisdictions or indicate cancer disparities based on certain demographics, grantees reference and include aspects of—to varying degrees—“rural” into each of their cancer control plans. Given the built-in collaborative nature that NCCCCP establishes—from community- and state-level stakeholder partnerships to the technical assistance provided by the CCNPP—the Committee believes grantees can bring greater awareness and attention to rural cancer mortality and address rural access-to-care challenges as these plans are critical blueprints that drive comprehensive cancer control activities for each jurisdiction. Therefore, the

Committee believes the inclusion and integration of rural-specific objectives and strategies to cancer control plans, where relevant, would further advance the goals of NCCCP while also reducing the disease burden for rural and underserved populations.

**Recommendation 5:** The Committee recommends the CDC require states, territories, and tribes or tribal organizations to assess rural-urban cancer mortality rates as part of their cancer control plans and, where appropriate, develop and implement rural-focused cancer control goals, objectives, or strategies, particularly in areas with high rural cancer mortality rates.

## CONCLUSION

As the second leading cause of mortality, cancer is a major public health burden that costs the U.S. health care system billions of dollars every year.<sup>xvi</sup> Among rural counties, all-cancer mortality is higher compared to urban areas; disparities in access-to-care, a higher likelihood of engaging in cancer-causing risk behaviors, and a population that tends to be older, poorer, and sicker may explain the widening gap in cancer outcomes for rural patients. Given the scale and scope of this issue, through its recommendations, the Committee emphasizes the importance of focusing on comprehensive, innovative, and sustainable solutions to close the rural-urban mortality gap and to continue reducing the disease burden nationally. Furthermore, the Committee highlights the need to develop and foster strategic partnerships. As seen through NCI's work on the LAUNCH project and its rural supplements to 21 NCI-designated Cancer Centers, these collaborations underscore the value that public-private partnerships can bring and ultimately what can happen when federal agencies come together to advance existing cancer control efforts.

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<sup>xvi</sup> Estimates from the Medical Expenditure Panel Survey (MEPS) report that [medical spending to treat cancer reached \\$88.3 billion in 2011](#), an increase from 2001 when estimates reached \$56.8 billion.

## APPENDIX A – SITE VISIT PROFILE

Established in 1971, [Northern Valley Indian Health \(NVIH\) Inc.](#) is a non-profit, tribal organization that was founded by a group of California tribal representatives from the region “seeking to reestablish health services for Indians in California.” At each of its seven locations in northern California—Chico, Red Bluff, Willows, and Woodland—NVIH clinics provide quality, patient-centered primary care, dental, behavioral health, and community health services to Native and non-Native patients. NVIH’s board of directors is comprised of tribal members from four federally recognized California Indian tribes: the Grindstone Indian Rancheria of Wintun-Wailaki Indians of California, the Mechoopda Indian Tribe of Chico Rancheria, the Cortina Indian Rancheria of Wintun Indians of California, and the Yocha Dehe Wintun Nation.

### Cancer Disparities in Indian Country

Much like the nation, cancer is a leading cause of death among American Indian and Alaska Native (AI/AN) populations.<sup>37</sup> Compared to their White counterparts, AI/AN people have an overall lower incidence rate for all cancers combined, but a higher all-cancer mortality rate with specific regional differences.<sup>38</sup> Based on 1990-2009 national data,<sup>^</sup> AI/AN all-cancer mortality was lower from 1990-1998, but higher from 1999-2009. All-cancer deaths were significantly higher for males and females living in the Northern Plains, Alaska, and the Southern Plains; across all IHS regions, AI/AN populations bore a significantly higher burden of death for cancers of the gallbladder, liver, kidney, and stomach.<sup>38</sup> (See [NCI’s video](#) for more about addressing cancer disparities among Native people.)

<sup>^</sup> Researchers limited their analyses to AI/AN populations living in [Contract Health Service Delivery Area \(CHSDA\)](#) counties; these are counties designated by the IHS for which “contract health services will be made available by the IHS to members of an identifiable Indian community who reside in the area...” Researchers also conducted their analyses on six regions: (1) Northern Plains, (2) Alaska, (3) Southern Plains, (4) Southwest, (5) Pacific Coast, and (6) East.

As recent as 2016, the UC Davis Comprehensive Cancer Center (UCDCCC) developed a relationship with the NVIH clinic in Willows. To expand on this relationship, in 2018, UCDCCC was one of 21 NCI-designated Cancer Centers to receive supplemental funding (refer to **Figure 2**). The project goal is to develop, implement, and evaluate a human papillomavirus (HPV) vaccination program that focuses on increasing vaccine uptake among rural and Native American adolescents, ages 11-17. As stated in [UCDCCC’s project abstract](#), “HPV vaccination coverage with at least one dose remains disproportionately lower among rural adolescents compared to adolescents residing in urban areas, and the rate of series completion is lower among Native American adolescent girls compared to non-Hispanic White adolescent girls.”

Since receiving funding from NCI, the UCDCCC-NVIH partnership has conducted an HPV Community Needs Assessment

(CNA), a clinic-wide staff training, and parent workshops and focus groups. From these activities, the partnership has learned about critical health education gaps and implications for policy. For example, from the HPV CNA, individuals confused HPV with HIV and individuals expressed a greater likelihood of receiving the vaccine if it was recommended by a provider and if the school required the vaccine.

Given the growing need for rural-specific research and interventions, especially among underserved populations, the Committee commends NCI’s work and recommends that NCI expand its rural cancer control program (see Recommendation 2) to reach rural, tribal, and underserved populations.

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