

## COMMENTARY

## “Taking the Bull by the Horns”: Four Principles to Align Public Health, Primary Care, and Community Efforts to Improve Rural Cancer Control

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**Disclosures:** No conflicts of interest were reported by the authors of this paper. The study sponsors had no role in study design; collection, analysis, and interpretation of data; writing the report; or the decision to submit the report for publication.

**Funding:** This study was supported, in part, by Cooperative Agreement Numbers U48-DP005017 and U48-DP005006 from the Centers for Disease Control and Prevention (CDC) Prevention Research Centers (PRC) Program and the National Cancer Institute (NCI), as part of the Cancer Prevention and Control Research Network (CPCRN). Melinda Davis was partially supported by an Agency for Healthcare Research & Quality (AHRQ) patient-centered outcomes research (PCOR) K12 award (Award # K12 HS022981 01) and an NCI K07 award (1K07CA211971-01A1) during manuscript preparation. The contents are solely the responsibility of the authors and do not necessarily represent the official view of the funders.

**Acknowledgments:** We are grateful for the support of our community partners in this work. Eliana Sullivan provided helpful edits on early versions of this commentary.

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doi: 10.1111/jrh.12263

**Key words** cancer prevention and control, health disparities, implementation science, participatory research, rural health.

To urban city dwellers, rural life can seem idyllic—a slower pace, easy-to-access outdoor recreation, and close ties to family, friends, and the community. What may not be as obvious is the extent to which persistent health disparities plague rural populations. For example, recurring evidence suggests that rural Americans face greater mortality risks from multiple diseases, including cancer, cardiovascular disease, and drug-related injuries.<sup>1,2</sup> In addition, rural Americans are more likely than urban Americans to have low incomes, to have no more than a high school education, to be unemployed, and to be uninsured.<sup>1,3-5</sup> Such data may compel stakeholders to seek to “save rural” by simply extending services and opportunities that exist and work well in urban environments. However, we argue that rural settings are fundamentally different in ways that require more creative thinking in order to optimize health outcomes. In this commentary, we summarize current trends in cancer prevention and control in rural areas and argue that 4 key considerations are needed when working in rural settings to address cancer disparities.

There is a growing interest in exploring and addressing health disparities in rural areas, particularly around cancer prevention and control.<sup>6-8</sup> Recently, Henley et al published “Invasive Cancer Incidence, 2004–2013, and Deaths, 2006–2015, in Nonmetropolitan and Metropolitan Counties—United States,” which highlighted increasing rural-urban cancer disparities.<sup>9</sup> The authors used national data from the Centers for Disease Control and Prevention’s (CDC) National Program of Cancer Registries (NPCR) and the National Cancer Institute’s (NCI) Surveillance Epidemiology and End Results (SEER) Program to show that nonmetropolitan rural areas had lower average annual age-adjusted cancer incidence rates for all anatomical cancer sites combined, but higher death rates than metropolitan areas. Moreover, over time, they found that the annual age-adjusted death rates for all cancer sites decreased at a slower pace in rural areas (–1.0% per year) than in metropolitan areas (–1.6% per year), thereby increasing rural-urban differences in cancer-specific mortality over time. Of particular note, rural counties had higher incidence of, and deaths from, cancers related to health behaviors (eg, lung cancer from tobacco use) as well as cancers that can be prevented by screening (eg, colorectal cancer). These potentially modifiable pathways suggest that multilevel intervention may be needed to improve cancer outcomes, with tailored attention to individual (eg, knowledge, behavior), clinic (eg, availability, accessibility of health services), and health system (eg, insurance) determinants.

While differences in cancer incidence may reflect differences in underlying risk factors in rural areas contrasted to urban areas, differences in cancer death rates likely reflect disparities in access to health care and timely cancer screening, diagnosis, and treatment.<sup>10</sup> One might think that geographic access is the greatest barrier to cancer screening and treatment in rural populations. Indeed, multiple authors have explored how travel distance and travel time influence cancer screening and treatment.<sup>11-15</sup> However, focusing entirely on geographic barriers to care masks underlying social determinants of poor cancer outcomes such as environmental conditions and limited employment and educational opportunities. Often, these social conditions are far more complicated and intractable to change. These socioeconomic conditions may influence cancer outcomes in multiple ways in rural settings, in that cancer prevention through smoking cessation and diet/exercise is less attainable, early detection through screening is more costly and harder to access, and guideline-recommended cancer treatments are inaccessible and unaffordable for an increasing number of families.

In the past year, many articles have been published in *The Journal of Rural Health* which help to illuminate rural-urban disparities in cancer-related outcomes.<sup>7,9,11,12,16-18</sup> These articles illustrate multilevel influences on cancer-related behaviors and differential outcomes observed in rural areas. For example, Vandyke and Shell<sup>18</sup> and Crosby et al<sup>16</sup> shed light on individual-level factors that may influence cancer screening behaviors in rural populations. Yao et al<sup>7</sup> explored the role of the Affordable Care Act (ACA), finding that rural populations in Appalachia experienced higher cancer incidence relative to other non-rural and non-Appalachian populations, which they suggested may correspond with several ACA provisions that allowed rural Appalachian individuals without previous health care coverage or access to health care to obtain cancer screenings. Importantly, an article by Liang et al highlighted changing trends in the impact of geographic and sociodemographic factors on colorectal cancer disparities over time for Medicare members.<sup>17</sup> These articles, which explored national as well as regional variation in screening and treatment, suggest that the interventions needed to address rural disparities may be regionally distinct, as well as different from those employed in higher- and lower-resourced urban settings.

Henley et al's article,<sup>9</sup> as well as others published in the past year,<sup>2,19,20</sup> have shown us that although cancer outcomes nationally are improving over time with better screening and treatment, for rural Americans, things are getting worse.<sup>7,11,12,16-18</sup> In our opinion, these articles point to 4 key opportunities for advancement of the science and practice of rural cancer control.

1. **Utilize existing data when possible and develop new methods for working with small sample sizes.** We need to identify and harness the power of innovative data sources and methods to conduct rigorous rural cancer surveillance. This includes sustaining existing mechanisms for tracking epidemiologic cancer data, such as the Behavioral Risk Factor Surveillance Survey (BRFSS), NPCR, SEER, and SEER-Medicare data. In addition, we need to create and advance novel and rigorous methods for tracking and analyzing cancer-related metrics in smaller sample sizes, a feature that helps to define rural, rather than excluding rural communities and population subgroups from our studies.
2. **Prioritize efforts to evaluate, adapt, and expand evidence-based interventions to rural areas using multidisciplinary research strengths.** The NCI, CDC, and other federal programs are increasing their focus on rural health.<sup>8</sup> Multidisciplinary teams consisting of public health, primary care, and community stakeholders working across the cancer care continuum are best suited to respond to an increased emphasis on rural health. Such teams should use partnered approaches to identify regional "hotspots," understand determinants of poor care and outcomes, and intervene meaningfully.
3. **Weigh the pros and cons of rural definitions and consider the interaction of geography with individual-level and regional factors.** Multiple federal- and state-level definitions of rural exist.<sup>21,22</sup> These definitions have been developed and revised over time and are often used by agencies to determine which regions are eligible for certain federal programs.<sup>23</sup> However, many of the common rural definitions were not developed with health policy, or health services research, in mind. As Hart et al note, these taxonomies often do not discuss important demographic, cultural, and economic differences across rural places.<sup>22</sup> Thus, cancer control researchers should carefully weigh the pros and cons of different "rural" definitions and explore opportunities to look at gradations of rural and the interaction of individual and multilevel factors with rural geographic designations.
4. **Utilize an equity-based participatory implementation science approach to improve and align research and quality improvement efforts.** The rapid influx of interest in rural health warrants a few points of caution. In particular, we should seek to: (1) limit opportunistic exploitation of rural communities as a research setting because they are in vogue, and avoid replicating the tragedies of "helicopter research" in other vulnerable populations, (2) understand that interventions found to be successful in urban settings

may need to be adapted for rural communities or developed de novo, and (3) recognize that rural areas are heterogeneous and that interventions should be aligned with local regional contexts and priorities. We believe these concerns can be best addressed through employing guiding principles of community-based participatory research and participatory implementation science (Ramanadhan, Davis, Armstrong, et al, in preparation). These approaches seek to conduct local engagement activities to understand determinants of poorer outcomes, implement evidence-based strategies that are designed to address local concerns and needs, and assess reach and impact of interventions. In many cases, this may require a longitudinal approach to partnership development that blends both research and community health development.<sup>24,25</sup> It may also require taking an equity rather than an equality approach—such that some rural areas and/or care settings may need additional support and infrastructure to generate data, set quality improvement goals, and to improve workflows prior to intervention implementation.

The textbox highlights the ways our teams are working to apply these 4 recommendations and to address rural-urban disparities in colorectal cancer through the Cancer Prevention and Control Research Network (CPCRN).<sup>26</sup> These anecdotes provide exciting examples of how academic partners, funders, and regional stakeholders are

working together to ensure that the best evidence reaches and benefits all members of the community, not just those in well-resourced, urban settings.

As a society, we risk wasting decades of public investment and scientific progress when a sizeable population of rural Americans cannot access health care. The ACA substantially decreased the number of uninsured rural Americans, eliminated the ability of insurance companies to deny coverage due to preexisting conditions such as cancer, and extended Medicaid coverage to countless low-income, rural-dwelling residents.<sup>27</sup> If the ACA is repealed, rural populations who gained health insurance through the ACA are the most likely groups to lose their insurance, putting them at high risk for inadequate cancer screening, follow-up, resolution, and treatment. In addition, with ACA repeal, high premium and high deductible health plans are likely to proliferate, stretching insured, rural Americans to their economic limits and leading to further inaccessibility of health care. The natural conclusion of this state of affairs is that rural-urban disparities may continue to worsen in the next decade and beyond, since those patients who are most underserved and who can least afford health care are least able to access the benefits of our tremendous medical discoveries. As some would say, “it’s time to take the bull by the horns” to leverage the unique qualities of rural communities to address the multilevel factors that contribute to rural cancer disparities.

### **Applying Rural-Informed Research Approaches to Colorectal Cancer Prevention Interventions**

Multiple tests are recommended for screening average risk individuals for colorectal cancer, including colonoscopy every 10 years as well as simple, annual fecal tests that can be completed in the comfort of one’s home. Yet, less than two-thirds of age-eligible persons report that they are up-to-date with colon cancer screening, with less educated, uninsured, and rural populations being less likely than their counterparts to report being up-to-date with colon cancer screening, more likely to be diagnosed with advanced stage disease, and more likely to die of colon cancer.<sup>28,29</sup> The authors of the recent MMWR manuscript suggest that in relation to cancer, observed rural disparities “could be attributed to differences in adherence to screening guidelines.”<sup>9</sup>

Through the CDC- and NCI-funded Cancer Prevention and Control Research Network (CPCRN),<sup>26</sup> researchers in North Carolina and Oregon are working with multiple public health, primary care, community, and insurance partners to address rural-urban disparities in colorectal cancer screening. These partners have explored the impact of multilevel factors on colorectal cancer screening,<sup>30</sup> assessed rural patient preferences for Fecal Immunochemical Tests (FIT) to inform local test selection,<sup>31</sup> and worked to identify which clinic and community-based interventions are most effective at increasing fecal testing in rural and vulnerable populations and when/how to implement them (Davis, Freeman, Shannon, et al., in preparation). These findings have been used to support technical assistance to Medicaid health plans in Oregon as they partner with primary care clinics to implement evidence-based interventions to improve colon cancer screening and reduced disparities in rural and urban populations. Additionally, these researchers have compiled and analyzed statewide data (from a variety of sources, including insurance claims, cancer registries, natural history, screening preferences, area resource files, Census, and other data) to better understand, in specific groups (eg, Medicaid enrollees, the uninsured, African Americans and Latinos, rural populations), how much a variety of colon cancer-focused interventions and policies would cost and how much they could improve colon cancer screening, early detection, and treatment.<sup>32</sup> The simulated findings have been used, for example, to inform the selective implementation of specific quality improvement demonstration projects in hotspot regions of North Carolina by mailing screening reminders with free home-based stool testing kits to Medicaid enrollees who are overdue for colon cancer screening (eg, direct mail programs).<sup>33</sup>

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