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### Authors

Ko, Linda K

Scarinci, Isabel C

Bouchard, Elizabeth G

et al.

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## A Framework for Equitable Partnerships to Promote Cancer Prevention and Control in Rural Settings

Linda K. Ko, PhD <sup>1,2,\*</sup> Isabel C. Scarinci, PhD, MPH,<sup>3</sup> Elizabeth G. Bouchard, PhD,<sup>4</sup> Bettina F. Drake, PhD, MPH,<sup>4,5</sup> Elisa M. Rodriguez, PhD <sup>4</sup> Moon S. Chen Jr., PhD, MPH,<sup>6</sup> Deanna Kepka, PhD, MPH,<sup>7</sup> Aaron J Kruse-Diehr, PhD <sup>8</sup> Christie Befort, PhD <sup>9</sup> Jackilen Shannon, PhD <sup>10</sup> Paige E. Farris, MSW,<sup>10</sup> Amy Trentham-Dietz, PhD <sup>11</sup> Tracy Onega, PhD<sup>12</sup>

<sup>1</sup>Department of Health Systems and Population Health, University of Washington, Hans Rosling Center for Population Health, Seattle, WA, USA, <sup>2</sup>Public Health Sciences Division, Fred Hutchinson Cancer Research Center, Seattle, WA, USA, <sup>3</sup>Department of Obstetrics and Gynecology, University of Alabama at Birmingham, Birmingham, AL, USA, <sup>4</sup>Department of Cancer Prevention and Control, Roswell Park Comprehensive Cancer Center, Buffalo, NY, USA, <sup>5</sup>Division of Public Health Sciences, Department of Surgery, Washington University School of Medicine, Alvin J. Siteman Cancer Center, St. Louis, MO, USA, <sup>6</sup>Division of Hematology and Oncology, School of Medicine, UC Davis and UC Davis Comprehensive Cancer Center, Sacramento, CA, USA, <sup>7</sup>College of Nursing, University of Utah, Huntsman Cancer Institute, Salt Lake City, UT, USA, <sup>8</sup>Markey Cancer Center, Cancer Prevention and Control Program, University of Kentucky College of Public Health, Lexington, KY, USA, <sup>9</sup>University of Kansas Medical Center, Cancer Prevention and Control, University of Kansas Cancer Center, Kansas City, KS, USA, <sup>10</sup>Oregon Health & Science University-Portland State University School of Public Health, Knight Cancer Institute, Portland, OR, USA, <sup>11</sup>Department of Population Health Sciences and Carbone Cancer Center, University of Wisconsin-Madison, Madison, WI, USA; and <sup>12</sup>Department of Population Health Sciences, University of Utah, Huntsman Cancer Institute, Salt Lake City, UT, USA

\*Correspondence to: Linda K. Ko, PhD, Department of Health Systems and Population Health, University of Washington, Hans Rosling Center for Population Health, 3980 15th Ave NE, UW Mailbox 351621, Seattle, WA 98195, USA (e-mail: lindako@uw.edu).

### Abstract

Rural populations continue to experience persistent cancer disparities compared with urban populations particularly in cancers that can be prevented or detected early through screening and vaccination. Although the National Cancer Institute and the larger cancer research community have identified rural community partnerships as the foundation for reducing the disparities, we have identified limited application of community-based participatory research in cancer prevention and control research. Guided by the Community-Based Participatory Research Conceptual Model and our collective experience, we provide a framework for a community–cancer center partnership that focuses on promoting health equity. In this commentary, we articulate that the partnership process must foster capacity for communities and cancer centers, strive for rural representation in clinical trials and biobanking, build a pipeline for dissemination and implementation research, and create a bi-directional flow of knowledge between communities and academic institutions. Authentic partnerships with rural communities should be the ultimate goal of cancer centers, and the process described in this commentary can serve as an initial platform to build capacity and continue to strive toward that goal.

The decline in cancer death rates across all counties in the United States provides an optimistic picture of national efforts to promote cancer prevention and control (1). Unfortunately, disparities in cancer incidence and cancer deaths persist across racial and ethnic groups, socioeconomic levels, and rural populations (2,3). The Centers for Disease Control and Prevention reported that although rural counties have lower annual age-adjusted cancer incidence rates over a 5-year period (2009–2013) compared with nonrural counties, they have higher annual age-adjusted death rates (2011–2015) for all cancer types combined (2). Rural counties also had higher cancer incidence and deaths

for cancers that can be prevented and/or detected early through screening, such as lung, laryngeal, colorectal, and cervical cancers (2). Other studies document higher rates of behaviors associated with cancer, including tobacco use, alcohol consumption, physical inactivity, poor diet, and lower adherence to cancer screening and human papillomavirus vaccinations among rural compared with urban counties (4–8). The purpose of this commentary is to articulate a framework on how equitable partnerships between National Cancer Institute (NCI)-designated cancer centers and rural communities might enhance cancer prevention and control.

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Rural patients face many challenges in accessing health-care services, including a lack of health-care providers practicing in rural areas (4,9). Only about 11% of physicians practice in rural areas, where, as of 2010, almost 20% of the US population resides (10). Furthermore, the United States is predicted to face a shortage of oncology physicians, which only broadens the gap in rural cancer care (11-13). The Health Resources and Services Administration designates medically underserved areas or health professional shortage areas based on having too few primary care providers or having shortages of primary care, dental, or mental health providers in a geographic area (14). The lack of providers creates challenges for both patients and providers as limited access to specialists often requires providers to take on multiple roles. For example, rural oncologists report having to manage not only their patients' cancer care but also their comorbidities, because primary care providers are sometimes uncomfortable treating patients undergoing active cancer treatment (15). Across the cancer continuum (prevention, screening, diagnosis, treatment, survivorship, and end of life), rural patients face limited access to cancer support providers (eg, oncologists, social workers, mental-health-care providers, physical and occupational therapists, palliative care specialists) and clinical trials. These barriers are frequently compounded by transportation issues (16), lack of broadband internet (16,17), and insufficient financial resources (9,18). Cumulatively, these inequities have been further exacerbated by the COVID-19 pandemic.

In response to rural cancer disparities, the NCI took a number of steps to better understand these disparities and improve cancer prevention and control efforts (19). The steps include reviewing extramural research portfolios focusing on rural cancer as well as conducting meetings and conferences with diverse stakeholders (eg, researchers, funders, clinicians, and community organizations) to build partnerships, better understand rural disparities, and set agendas that address research and health-care practice gaps in rural cancer prevention and control (19). Additionally, funding opportunities became available to build rural research capacity across NCI-designated cancer centers and the larger cancer research community. These funding opportunities intentionally promote collaboration with local clinics and community organizations in underserved and underresourced rural settings by focusing on one or more stages of the cancer care continuum (20). As NCI-designated cancer centers and the larger cancer research community collectively mobilize their resources to improve rural cancer prevention and control, a critical element of success will be developing authentic partnerships with rural communities and building infrastructure to address the communities' priorities and plan for sustainability.

Over the past 2 decades, community-based participatory research (CBPR) has moved to center stage in intervention development and dissemination and implementation (D&I) research, with increasing recognition that community partnerships enhance intervention relevance to local context, reduce disparities, and improve health status (21,22). This commentary articulates a framework for equitable and transformative community-cancer center partnership guided by the CBPR Conceptual Model (23), our collective experience, and lessons learned from our rural consortium.

## CBPR Processes and Practices

The CBPR Conceptual Model includes 4 dimensions (contexts, group dynamics and equitable partnerships, intervention and research design, and outcomes) with embedded subdimensions

and relationships between the dimensions (see Figure 1). The details of the dimensions and subdimensions have been reported elsewhere (23). In brief, the first dimension—context—and its subdimensions, including social determinants (economic, social, and cultural), are described as shaping the nature of the research and the partnership. The second dimension is group dynamics and equitable partnerships, which describe how the practice of partnership creates equitable collaborations. The model shows that group dynamics and equitable partnerships interact with contextual factors to impact the intervention and research design. The intervention and research design dimension highlights the importance of integrating community partners' voices, cultural norms, and knowledge into the research design, methods, intervention development, and translation of knowledge for D&I (23). The bidirectional learning between communities and academics continues to build partnership synergy. Finally, ongoing interaction between the context, group dynamics and partnership processes and integration of community into the intervention and research design lead to the fourth dimension—outcomes. Outcomes include intermediate system and capacity changes for both the community and research institution, such as changed policy and practices, different power relations where community voices are heard, sustainability of community-centered interventions, and cultural revitalization and renewal, which collectively improve health and social justice outcomes. The model posits that partnership should be dynamic, and participating stakeholders may experience tensions because of loss of funding, new leadership, differences in partners' interpretation of events, and other external and internal factors.

## CBPR Considerations in Rural Setting

Although the 4 dimensions and their subdimensions of the CBPR Conceptual Model deserve equal attention, cultural factors are noteworthy, as they shape patients' risk, protective factors, and their engagement with health systems (24). In some rural communities, cultural factors may be manifested more subjectively and interrelated with race (25,26). Research conducted among rural Black and White adults from North Florida showed that cultural factors manifested into preferences on *how* patients wanted to be engaged with the health-care system, and these preferences were also intertwined with race (27).

Cancer patients and caregivers' experiences in Appalachia have been explained through an interrelated framework of 3 cultural models: Independence-Through-Work model, the Christian Community model, and the Appalachian Modern Worldview model (28). The Independence-Through-Work model posits that independence, personal virtue, and individual success are deeply interwoven with ideas of work and providing for family. The Christian model complements the Independence-Through-Work model by placing personal independence into a broader social context. For rural Appalachian cancer patients, this may mean prioritizing social obligations, to be deemed acceptable in broader social relations. The Appalachian Modern Worldview model features a set of values that blend the classic modern worldview with local traditions (29). Understanding these rural experiences can influence the success or the failure of CBPR processes and outcomes (24).

We propose that CBPR principles can be applied to community-cancer center partnerships in 4 ways: building a systems-level collaboration, fostering rural community and cancer center capacity to participate in research, increasing representation

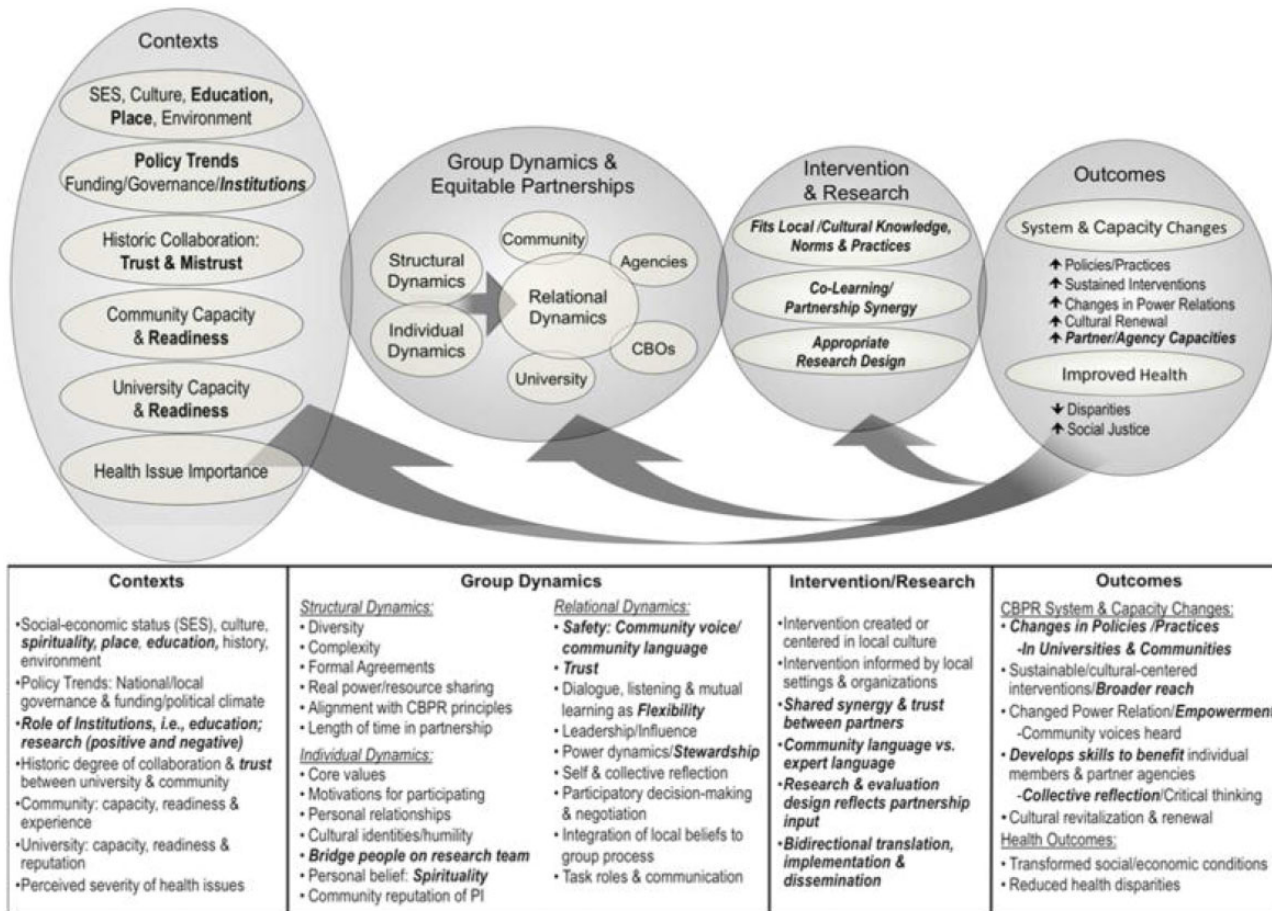


Figure 1. Conceptual logic model of community-based participatory research from process to outcomes. Adapted from Wallerstein N, Oetzel J, Duran B, Tafoya G, Belone L, & Rae R. What predicts outcomes in CBPR. In: Minkler M, Wallerstein N, eds. *Community-based Participatory Research for Health: From Process to Outcomes* 2nd ed. San Francisco, CA: Jossey-Bass; 2008:371-392. By permission of Jossey-Bass. Original model developed on 2011. Bold text denotes revisions made to the model in 2013. CBO = community-based organizations; CBPR = community-based participatory research; PI = principal investigator; SES = socioeconomic status.

of rural communities in clinical research and biobanking, and creating a pipeline for D&I of research findings to rural communities. For this article, we use the definition of community from the Centers for Disease Control and Prevention, which includes specific organizational entities within the community, as well as the broader community defined by geographic areas sharing cultures, values, and norms (30). Thus, some description of partnerships may be focused on organizations within the community and others to the broader community. We argue that both levels of partnerships are necessary for a successful progression of equitable outcomes.

## Partnerships That Build a Systems-Level Collaboration

Although progress has been made to translate research to practice, underserved populations, including rural residents, continue to benefit less from research efforts than their urban counterparts for various reasons. First, academic institutions and community organizations may use different approaches to address health priorities, and community organizations and community members are often not consulted on the design and conduct of research projects. Second, community organizations and community members may not have access to research

findings or may see research findings as not applying to them if their specific community and its culture were not directly considered in the research. Third, if partnerships are established between academic institutions and community programs, they are often based on a biomedical model rather than participatory research or empowerment models. Fourth, community organizations typically do not have the electronic health records capabilities that academic institutions have; thus, data collection and analyses must be adapted to the community's capacity. Fifth, some rural communities may be located hundreds of miles from the nearest academic medical center or NCI-designated cancer center. Hence, to truly engage individuals experiencing cancer disparities, changes in paradigms must be made throughout the research process.

A number of efforts have been successfully implemented in the context of racial and ethnic and rural disparities in the United States (31-34). CBPR is a philosophical framework where community members share responsibilities and strategic decision making with academic partners, and solutions are implemented in partnership with community members, rather than placing academics or health-care professionals in decision-making roles for the community. Potvin and colleagues (35) proposed 4 principles for implementing participatory research and interventions: "(a) integration of community members as equitable partners; (b) integration of intervention and evaluation; (c)



organizational and programmatic flexibility; and (d) utilization of the project as a learning opportunity for all.” However, as with any paradigm shift, this is an intensive process in which academics and community members need to recalibrate expectations, negotiate resources, and above all, be truly committed to reducing health disparities.

### Partnerships That Foster Rural Community–Cancer Center Capacity to Participate in Research

For cancer centers and academics to conduct effective research in rural communities, they must ensure that rural community partners and cancer centers have adequate capacity to conduct research. Increasing community capacity can enhance readiness to participate in research (36). Weiner (36) described organizational readiness as consisting of 2 components: 1) shared commitment in making particular changes and 2) organizations’ collective efficacy to do so. The  $R = MC^2$  heuristic expands on the concept of organizational readiness (R) using the following components: 1) motivation for implementation (M); 2) general capacities (C) of an organization; and 3) specific capacities (C) needed to implement a particular evidence-based intervention (37). Multiple factors influence clinical and community partners’ perceptions of each of these components including their perceptions of the relative advantage or the complexity of implementing one program over another. However, innovation-specific capacities can be facilitated by a strong clinic or community champion or opinion leader and the existence of positive interorganizational relationships (37–40). Motivation and capacities vary by type of community partner, culture, organizational climate, and the resources available to them (41,42).

Academic cancer centers must invest their time, resources, training, and personnel to support community–academic partnerships. Cancer centers should first conduct a needs assessment to understand whether cancer center resources, practices, and policies are conducive to establishing and sustaining rural community–cancer center partnerships. Cancer center policies and practices tied to research metrics are often narrowly focused on scholarly activities and do not recognize the time-intensive efforts needed to build community capacity. Activities beyond scholarly productivity, such as researchers’ engagement in community–academic capacity building, should be valued equally and have designated funding aligned with them.

In rural settings, capacity building often requires creative approaches, as rural areas may have fewer resources than urban areas. Therefore, rather than creating an intervention that requires new resources and infrastructure, the partnership should leverage existing community hubs to engage community members; better use technology such as telehealth in remote regions; and involve diverse groups of care teams that include patient navigators, nurses, and community health workers (43). Partnerships may increase community capacity by providing community health workers and rural providers with continuing education credits, partnering with lay health workers and church leaders to deliver behavioral health interventions (eg, cancer screening education), and using hub-and-spoke models to train patient navigation teams to link patients to follow-up care (34,44–50).

### Partnerships That Strive for Representation in Clinical Research and Biobanking

Rural cancer patients face many challenges with representation in clinical cancer treatment and prevention trials as well as

participation in biobanking (51–53). More recently, there has been renewed attention on cancer health inequities in rural populations following a report from the Cancer Moonshot Task Force highlighting needs among populations that reside far from cancer centers (51,54). Addressing rural cancer disparities involves improving representation in research and clinical trials across the cancer continuum, including primary prevention, treatment, and survivorship. Studies conducted in select rural regions of the United States highlighted resource needs as well as recruitment barriers, motivators, and community-based strategies to increase clinical trial participation among rural populations (9,51,55–60).

### Recruitment Barriers and Motivators

Common barriers to cancer clinical research accrual reported by rural health-care providers, patients, and communities include trust (51,57); clinical providers’ lack of awareness of appropriate clinical trials (56,61–63); time commitment (57); monetary burden to participants not covered by insurance (58); travel (9,51,58); patients’ lack of knowledge about clinical studies (51,57,58); and discouragement or lack of recommendation from a clinical provider (56,58). Geana and colleagues (59) found that compared with urban cancer patients, rural cancer patients were less likely to report discussing clinical treatment trials with their providers, and they held more negative views of clinical trials, such as perceiving trials as a last-resort option and fearing being assigned a placebo. Friedman and colleagues (57) investigated rural community members’ motivators for participating in a clinical trial and identified receipt of a financial incentive as one motivator, though that alone was deemed insufficient. Other motivating factors included the following: the research study involved a hereditary condition that could impact their family; the research could benefit a family member suffering from a condition in which a current treatment was not working; and receiving thorough information about available clinical trials and details on clinical trial protocols (57).

### Recruitment Strategies: Implementation Gaps and Research Opportunities

Suggested approaches to increase accrual in cancer clinical trials (both treatment and nontreatment trials) and biobanking participation included the following strategies: 1) working with community and faith-based organizations (eg, schools and churches) that have established community trust (57); 2) partnering with primary care clinical providers or relevant specialists (eg, urologists) who are seen as trusted providers and could recommend a clinical trial to patients (51,56,58,64); 3) disseminating research opportunities through publications from trusted health systems or agencies (eg, Council on Aging and AARP) (51); and 4) for prevention trials, linking trial information to employee wellness program health assessments (65) or cancer screening events such as mobile mammography (66). Patient navigator programs may also play a key role in promoting equal access to clinical trials among rural patients, similar to efforts that improve access for racial and ethnic minority patients (67). The relationship across these 4 strategies is the importance of built-in trust when linking rural cancer patients to clinical trial research opportunities.

Access to clinical trials through provider referrals is a major driver of disparities in clinical trial participation (68). Those who follow National Comprehensive Cancer Network guidelines,

which posit that the best management of any patient with cancer is in a clinical trial, incorporate promotion of clinical trial participation as standard of care (69). The Association of Clinical Oncology advocates for Medicaid to “cover routine care costs” associated with clinical trial participation (70). Health-care providers are the most trusted sources for information on clinical trials (71), and patients who have supportive and informative interactions with providers about clinical trials are more likely to participate (72). Thus, initiatives are needed to increase rural community physicians’ participation in clinical research, including those practicing in frontier and remote rural settings. For example, the National Community Oncology Research Program has expanded designated minority and underserved community sites to include sites focused specifically on enhancing rural participation in cancer prevention, treatment, and care delivery trials (73).

Collaboration with National Institutes of Health–supported translational research networks can also serve as a strategy to increase rural participation in trials. Administered by National Institutes of Health’s National Center for Advancing Translational Sciences, the Clinical and Translational Science Award programs are hubs for catalyzing discoveries across the translational science spectrum and accelerating dissemination of treatments to patients (74). The Institutional Development Award Program Infrastructure for Clinical and Translational Research is another translational research network located in states serving large rural areas (75). These translational research networks create collaborative relationships with cooperative extension systems, where the extension regional offices serve as intermediaries between rural community and academics, connecting community leaders to academic researchers, endorsing research studies, enhancing credibility, and bridging the latest medical research and innovation to the community (76).

However, a substantial gap remains in implementation research regarding the feasibility of adapting clinical trial recruitment strategies. Specifically, strategies should use a systematic approach within rural health-care settings that consider drivers and deterrents, including patient, provider, and health-care system factors. In addition, research is also needed to understand the potential realm of untapped points of access for accrual to cancer clinical trials. Primary care providers and other relevant specialists who serve rural populations are potential implementers and adopters and often have more clinical reach in rural communities than oncologists and cancer centers (56). Ultimately, rural health-care infrastructure is paramount to any of the suggested strategies. Furthermore, acknowledging that cancer care occurs within a broader health-care environment emphasizes the complexity of intertwined systems and the importance of functional bidirectional linkages and communication. These factors are complicated in rural settings where cancer care and primary care occur in different health-care systems, and the clinical trial occurs in yet a third, the academic system. Distance between the referring provider’s clinical practice and the research center is inversely associated with clinical trial referral rates (77). Research is needed on implementation strategies to enhance communication and referrals across health-care systems that are separated by physical, structural, and even cultural distances.

Strategies that incorporate the role of primary care providers and oncologists in rural settings should consider the full range of cancer prevention, treatment, and survivorship trials. Addressing access to both treatment and behavioral prevention trials (eg, cancer screening, smoking cessation, or lifestyle changes) will ultimately impact rural cancer disparities across

the cancer continuum. In addition, bona fide engagement of local providers to demonstrate the potential gains from rural research participation (eg, increases in HEDIS measures) rather than reliance on practice databases to access patients will help ensure trials are clinically relevant and feasible in rural settings, have wider reach, and thus enhance referral rates (70). For example, a lifestyle behavioral intervention trial in rural primary care clinics found that high provider involvement doubled the proportion of participants who were referred to the trial by a provider (78). Strategies to engage providers need to be tailored to each clinic’s unique cultural and environmental context (79).

Cancer clinical trials, including biobanking participation, and cancer prevention and control across the cancer continuum are components of cancer care, but such a perspective is not well understood by patients and communities. Most patients view clinical trials as important to oncologists or researchers and of less value to themselves (58). However, as efforts in precision oncology and immunotherapy increasingly require bio-specimens and continuously integrate into clinical care, there is a greater need to emphasize the value of research to patients, including those in underserved rural populations. Representation and informed decision making are essential components in clinical trial research and cancer prevention initiatives as they are directly tied to reducing research inequities. Explaining the relevance and importance of representation in cancer research and participation in biobanking are low-resource strategies to enhance informed decision making among underserved and underrepresented populations.

## Partnerships That Accelerate D&I of Intervention and Practices to Improve Health Equity and Outcomes

A priority within rural cancer control is designing effective and innovative strategies that can be translated into tools and resources for public health practice. Scientific advances are often developed in highly controlled academic medical settings with limited input from the community; this means that they are created without rigorous data triangulation to understand key aspects of the setting, including local culture, history, and politics (23). To address health equity—defined in the recent Presidential Executive Order as “the consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as persons living in rural areas” (80)—research must ensure inclusion of rural individuals and communities to generate representative evidence and appropriately tailor translation of that evidence into rural populations.

D&I research is marked by trials conducted in real-world settings (81). These types of research studies are designed to evaluate the effectiveness and feasibility of administering the interventions in diverse contexts using the infrastructure, staff, and resources in a given environment (82). Such research is a critical pillar of health equity, improving the use of evidence-based intervention and practice outside of academic medical contexts. One major outcome of a robust community–cancer center partnership is the engagement of local stakeholders in D&I research from the beginning (83). Local stakeholders can shape the direction of the research and ensure that the research includes the larger community’s perspective as well as a nuanced understanding of the local context. Such understanding will help establish a more robust pipeline for adoption,

sustainability, and ultimately transformative changes in different sectors of the community including clinicians, administrators, and policy makers.

Whereas partnerships with community have been extensively documented, partnerships with other public health initiatives have been described less often. A number of thematic networks have been established by NCI and other institutes and organizations that inform a model of rural cancer control research and partnerships between community clinical practices and academic institutions. The intent of these community clinical research networks is to reflect the cancer-related care that occurs mostly in the community, rather than at large academic cancer centers, and to promote participation of individuals in research, even if they do not reside near such centers. These networks support clinics and researchers to identify and implement shared approaches along the cancer control continuum in rural areas. The efforts of these networks have addressed some of the common barriers to rural cancer research, including lack of research infrastructure, low recruitment, and absence of tailored materials to rural context.

Through affiliation or translation of findings into local practices, these networks can extend rural research capacity. Community organizations and clinics can learn from and interface with national networks in ways that can benefit their patient populations. In some cases, evidence generated from large networks can be adopted by community clinics, often with context-specific adaptations. Developing a simple resource repository of curated national resources, providing community sites access to these resources, and monitoring its use can keep sites abreast of research findings.

## Discussion

Despite national efforts to promote cancer prevention and control, rural populations experience striking disparities compared with urban populations in cancers that can be prevented or detected early through screening and vaccination. In response, the NCI and the larger cancer research community have identified rural community partnerships as a critical element for reducing these disparities. As CBPR has moved to center stage in intervention and D&I research, we have found limited application of CBPR in cancer prevention and control research. Guided by the Community-based Participatory Research Conceptual Model and our collective experience, we propose a community-cancer center partnership framework that focuses on health outcomes that foster health equity. We argue that the partnership process needs to foster capacity for both communities and cancer centers, strive for rural representation in clinical trials and biobanking, build a pipeline for D&I research, and share and learn with other community-academic public health initiatives. Authentic partnerships with rural communities should be the ultimate goal of cancer centers, and the process described in this article can serve as an initial platform to build capacity and continue to strive toward that goal.

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No new data were generated or analyzed in support of this research.

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