PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY

Community Engagement and Population Health

U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

About the Journal

Preventing Chronic Disease (PCD) is a peer-reviewed public health journal sponsored by the Centers for Disease Control and Prevention and authored by experts worldwide. PCD was established in 2004 by the National Center for Chronic Disease Prevention and Health Promotion with a mission to promote dialogue among researchers, practitioners, and policy makers worldwide on the integration and application of research findings and practical experience to improve population health.

PCD's vision is to serve as an influential journal in the dissemination of proven and promising peer-reviewed public health findings, innovations, and practices with editorial content respected for its integrity and relevance to chronic disease prevention.

PCD Staff

Leonard Jack, Jr, PhD, MSc
Editor in Chief

Lesli Mitchell, MA
Managing Editor

Brandi Baker, MBA
Production Coordinator
Contractor, Akima Data Management

Kim Bright, PMP
Information Technology Project Manager
Contractor, Akima Data Management

Kate Harris, BA
Technical Editor
Contractor, Akima Data Management

Ivory M. Jones, MS
Editorial Assistant
Contractor, Akima Data Management

Shawn Jones
Software Engineer
Contractor, Akima Data Management

Camille Martin, RD, LD
Senior Technical Editor

Susan McKeen, BA
Senior Software Engineer
Contractor, Akima Data Management

Rosemarie Perrin
Technical Writer-Editor
Contractor, Akima Data Management

Sasha Ruiz, BBA
Health Communications Specialist

Robin Sloan, MA
Technical Editor
Contractor, Akima Data Management

Martin Steib, BA
Multimedia Specialist
Contractor, Akima Data Management

Ellen Taratus, MS
Senior Technical Editor
Contractor, Akima Data Management

Caran Wilbanks, BA
Lead Technical Writer-Editor

Associate Editors

Arsham Alamian, *PhD, MSc, FACE*

Semra Aytur, *PhD, MPH*

Ronny A. Bell, *PhD, MS*

Jeane Bosch, *PhD, MPH*

Tammy Calise, *DrPH, MEd*

Lucas Carr, *PhD*

Sajal Chattopadhyay, *PhD*

Benjamin W. Chrisinger, *PhD, MUEP*

Kar-Hai Chu, *PhD, MS*

Sarah Conderino, *MPH*

Kenneth Cummings, *PhD, MPH*

Patricia Da Rosa, *DDS, MPH, MSc*

Jason A. Douglas, *MA, PhD*

Mike Dolan Fliss, *PhD, MPS, MSW*

Brian Hendricks, *PhD, MSci*

Lucine Francis, *PhD, RN*

Janessa Graves, *PhD, MPH*

Z. Tuba Suzer Gurtekin, *PhD, MS, MBA*

Jeanette Gustat, *PhD, MPH*

Daikwon Han, *PhD*

Natalie D. Hernandez, *PhD, MPH*

Linda D. Highfield, *PhD, MS*

Dylan Jester, *PhD, MPH*

Nan Jiang, *PhD*

Marynia Kolak, *PhD, MS, MFA*

Jessica A. Kulak, *PhD, MPH, MS*

Amos Lal, *MBBS, MD, FACP*

Lihua Li, *PhD*

Zhen-Qiang Ma, *MD, MPH, MS*

Amyn A. Malik, *PhD, MBBS, MPH*

Lohuwa Mamudu, *PhD*

Kevin Matthews, *PhD, MS*

Katerina Maximova, *PhD*

LaToya J. O'Neal, *PhD, MS*

Michael J. Parks, *PhD*

Carolina Pérez Ferrer, *PhD, MSc*

Austin Porter III, *DrPH, MPH*

Irene Prabhu Das, *PhD, MPH*

Jessica M. Robbins, *PhD*

Richard Casey Sadler, *PhD, MPH*

Lia Scott, *PhD*

Michael L. Sells, *PhD, MS, CHES*

Jayme Steig, *PharmD, RPh*

Mikiko Terashima, *PhD, MSc*

Tung-Sung Tseng, *PhD, MPH*

Camille Vaughan, *MD, MS*

Kristina Vatcheva, *PhD, MS*

Neng Wan, *PhD, MS*

Arica White, *PhD, MPH*

Korede Yusuf, *PhD, MBBS, MPH*

Eun-Hye Enki Yoo, *PhD*

Guixiang (Grace) Zhao, *MD, PhD*

Table of Contents

10. **A Communitywide Collaboration to Increase Enrollment, Retention, and Success in Evidence-Based Lifestyle-Change Programs in Racial and Ethnic Minority Populations**
    Kepper M, Stamatakis KA, Mudd N, Deitch A, Terhaar A, Liu J, et al. A Communitywide Collaboration to Increase Enrollment, Retention, and Success in Evidence-Based Lifestyle Change Programs in Racial and Ethnic Minority Populations. Prev Chronic Dis 2023;20:220352.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 22, E25 JUNE 2025

GUEST EDITORIAL

Harnessing the Power of Community Engagement for Population Health

Tabia Henry Akintobi[1]; Robert E. Bailey II, MPH[2]; J. Lloyd Michener, MD[3]

Accessible Version: www.cdc.gov/pcd/issues/2025/25_0189.htm

Suggested citation for this article: Akintobi TH, Bailey RE II, Michener JL. Harnessing the Power of Community Engagement for Population Health. Prev Chronic Dis 2025;22:250189. DOI: https://doi.org/10.5888/pcd22.250189.

PEER REVIEWED

Community engagement has a long history in public health and in the prevention of chronic disease (1,2). In 1997, the Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR), published the first edition of the *Principles of Community Engagement*, noting that community involvement and collaboration had become the foundation of public health action (3). In 2011, a second edition was developed in partnership with the Clinical and Translational Science Awards (CTSA) Program of the National Institutes of Health (NIH). It added the concept of engagement as a continuum from outreach to shared leadership, examples from the field, and implementation and evaluation guidance (4). A third edition was published in 2025 as a collaboration among the CTSA Program, NIH, ATSDR, and CDC, with some 165 authors spanning community organizations, academia, and federal agencies (5).

Definitions of community and community engagement and their key elements have evolved. The third edition of the *Principles of Community Engagement* notes that communities can be thought of as a group of people with diverse characteristics who are linked by social ties, shared common perspectives and identity, and engagement in joint action. A single person may belong to many communities (5). Community engagement is the process of building sustainable relationships through trust and collaboration that strengthens community well-being. The process should be enduring, equitable, and culturally sensitive to all participants, with a shared goal of addressing the concerns of the community. The third edition adds the principle of trustworthiness as a fundamental element in sustaining community engagement and advancing health equity (6).

The National Academy of Medicine launched a major effort on meaningful community engagement in health with a primary report released in 2022 (7). An organizing committee of community leaders, researchers, and policy advisors was charged with compiling and assessing community-engaged and evidence-based tools that could be used to ensure that engagement is meaningful to communities. The organizing committee realized the need for a new conceptual model that illustrates the dynamic relationship between community engagement and improved health and health care outcomes. The new model highlights the centrality of community engagement; the core principles required for meaningful, successful, and sustained engagement; and how meaningful engagement leads to strengthened partnerships, expanded knowledge, improved health, and transformed systems that provide everyone with the opportunity for health. A linked set of stories and measurement instruments are provided, mapped to domains of the conceptual model (Figure).

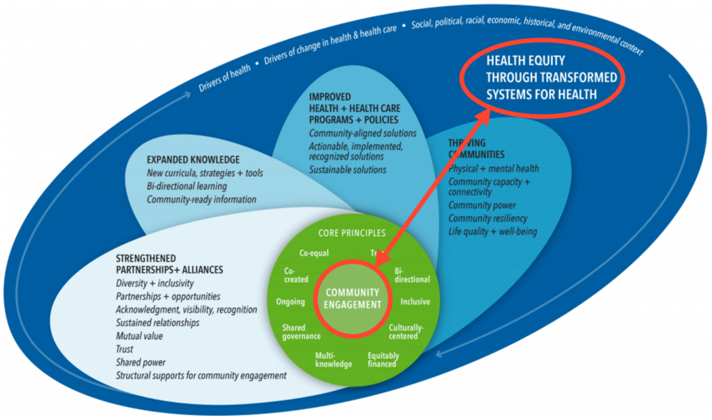


Figure. A conceptual model to advance health equity through transformed systems for health. Elements in red were added by the authors. Adapted with permission from the National Academy of Medicine. The model is available online at https://nam.edu/product/achieving-health-equity-and-systems-transformation-through-community-engagement-a-conceptual-model.

Interest in community engagement in public health continues to grow. A 2021 bibliographic mapping of the topic noted more than

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

1,100 publications; the number of publications increased sharply from 1980 to 2020 and half of the published reports were from the US (8). These models and their applications to public health were discussed in a recent editorial in the *American Journal of Public Health* (9). Other recent reports detail multisectoral community-engaged research and practice programs and models addressing underlying determinants (10,11). A toolkit and discussion guide on trustworthiness was developed by the Center for Health Justice of the Association of American Medical College with extensive community guidance, reflecting the need for enhanced attention to trust and trustworthiness (12).

Together, these reports heighten the emphasis on the role of community engagement in public health. Recent publications in *Preventing Chronic Disease* (PCD) also highlight the role of community engagement, including examples of how and where engagement has been supported and effective so that public health efforts to prevent chronic disease are trustworthy, effective, and sustained.

PCD Collection on Community Engagement and Population Health: From Practice to Evaluation

This collection of 9 PCD articles focuses on community engagement in public health, from practice to evaluation. Historically, community engagement has been commonly found in formative research activities, informing development of communication strategies, messages, and tools, as well as prioritizing issues and policy solutions. Brewer et al describe 2 boot camps to develop locally relevant materials on the risk of human papillomavirus among vaccine-eligible children, adolescents, and young adults, noting differences in both messages and presentation methods developed by various communities and reinforcing the value of local community input (13). Olson et al describe identification of hot spots for female breast cancer and lung cancer and a statewide effort, led by the Advancing a Healthier Wisconsin Endowment, to engage people from different backgrounds and communities about the causes and potential strategies for addressing disparities (14). Listening sessions noted a broad range of contributors to cancer disparities, areas with shared knowledge, and areas in which further discussion and education (both of the public and scientific community) were likely needed. Researchers were noted to have general knowledge of the role of social context in cancer disparities, while community participants had extensive knowledge of the complex community-specific interplay between social relationships, social conditions, and policy.

Communities have been increasingly involved in mapping strategies to prioritize needs and interventions. Payán et al describe application of a mapping component for a multilevel church-based intervention that used community-based participatory research to prevent obesity among church members in South Los Angeles (15). Multiple dimensions of food insecurity were documented, varying across neighborhoods, as was the need for additional work on translating mapped data to policy and local environmental interventions. Thompson et al used community-engaged concept mapping to generate consensus on priorities for care, research, and cancer control in Kentucky (16). Adult community members and staff members of statewide and community-based partner organizations were recruited to participate in a video-conferencing concept mapping process. These researchers found a high rate of congruence among topics and potential strategies. Keller et al describe a community–academic partnership between residents of Milwaukee’s Near West Side and Marquette University to generate, sort, and rate maps of clusters of concepts of a healthy community, showing how new tools can bring together ideas that have broad support and become the foundation for strength-based solutions aligned with partner priorities (17).

Other articles in this collection reinforce the idea that community engagement needs to be a deliberate effort with tangible results. Carnahan et al describe how the Illinois Department of Public Health adopted a robust community- and legislative-engaged approach that reflected the voices of people affected by cancer and the diverse needs and assets in the state (18). DeBruyn et al describe the design, implementation, and evaluation of community-defined strategies to address type 2 diabetes across 17 tribes and tribal communities by focusing on traditional foods, physical activity, and social support (19). Using a mixed-method evaluation, they found an increase in targeted activities, challenges in evaluation when multiple groups work together, and the need for sustained community infrastructure. Elliott et al describe an extensive community health program with some 25 community partners and Duquesne University, coordinated by the Allegheny County Health Department (20). The program included community-based screening with counseling by a pharmacist and referral to additional clinicians and/or community service providers. Qualitative evaluation found that the program provided needed services but was hampered by challenges in follow-up, inadequate community resources, and need for sustained funding.

Finally, Kepper et al describe a more than 2-year process by multiple community-based health organizations in St. Louis metropolitan areas to address, test, and evaluate interventions to optimize health for all, particularly those living in a federally designated Promise Zone (21). This complex project evolved throughout the

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

COVID-19 pandemic, accelerated activities to online platforms, expanded internet accessibility for people with poor connectivity, and demonstrated the resilience of engaged community groups.

Where We Go From Here

Community engagement is central to public health and chronic disease prevention. The articles in this collection showcase examples of engagement with local and state communities. They use data and community wisdom to inform decision-making, adaptation, and implementation; highlight the resilience of communities; and document challenges in program implementation, follow-up, and sustainment. These articles and their examples, together with other national work on community engagement in health, yield several recommendations for public health practitioners:

- Go to communities to learn their perspectives, strengths, values, and priorities. This is central to intentional relationship-building, reflecting the value of community members and groups as central to planning, implementing, evaluating, and sustaining programs and research that matters. Despite funding challenges, this practice is central to trust, must be built over time, and should not be rooted in the acquisition or administration of a grant.
- Amplify and credit the community wisdom central to ideation, process, implementation, evaluation, and recommendations, including investigator status, compensation, co-authorship, co-presentation, and co-branding.
- Address institutional and organizational barriers to and needed investments in community-engaged prevention practice and research. Barriers may reflect deep-seated administrative structures that threaten efficiency and trust even among the most well-meaning, mission-aligned partners.
- Partner with health care, social service, business, faith, and nongovernment organizations to address social and political factors associated with health and health care. These potential partners are often underused, despite their services and ability to influence health priorities such as housing, workforce development, food access, and primary health care.
- Support community-led projects and infrastructure central to sustained success. Mechanisms that position communities as senior or principal investigators of prevention programs and research are essential to powering (not empowering) their leadership and sustaining their programs. This value and practice must be bolstered by partnerships and resources for rigorous and robust data collection and analysis to demonstrate impact and outcomes.
- Address and eradicate rampant health misinformation and disinformation by reimagining public health communication, in partnership with community influencers, resulting in messages that are not only accurate but attend to social motivation, lived experiences, and trusted sources across the spectrum of mass and social media communication.
- Advocate for community-led public health improvement. Community-informed data systems, metrics, and networks should not only drive responsive research, practice, and clinical care but also be the change that dismantles systemic and structural barriers to health through local, regional, and national policy.
- Practice the values of listening to understand, cultural humility to translate, and trustworthiness to build and trust.
- Respect community strengths and avoid the idea that communities lack resources and need the preconceived solutions of outside groups to solve problems within the community.

Together these practices will expand community-engaged public health research, practice, and action and build community trust. Community-engaged prevention of chronic disease is realized through integrated efforts in education, research, clinical care, and service, in collaboration with partners committed to improving health outcomes and addressing the root causes of health inequities. These root causes are embedded in systems, conditions, and contexts that support or prohibit optimal health. Public health practitioners who embody these values engage in early and sustained community assessments to deepen understanding of local assets, needs, histories, and power dynamics.

Community engagement has been identified as a core attribute of public health for 4 decades and is a necessity for building trust in the decades to come. Preventing chronic disease occurs through the active, meaningful engagement of communities, who co-design, implement, and evaluate the programs or research they prioritize and which they decide to lead, support, and sustain.

Acknowledgments

The content is solely the responsibility of the authors and does not necessarily represent the official views of CDC or the US government. The authors received no external financial support for the research, authorship, or publication of this article. The authors declared no potential conflicts of interest with respect to the research, authorship, or publication of this article. The authors received permission to reproduce the figure included in this article.

Author Information

Corresponding Author: Tabia Henry Akintobi, PhD, MPH, Morehouse School of Medicine, 720 Westview Dr, Atlanta, Georgia 30310 (takintobi@msm.edu).

Author Affiliations: [1]Prevention Research Center, Morehouse School of Medicine, Atlanta, Georgia. [2]Centers for Disease

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Control and Prevention, Atlanta, Georgia. [3]Department of Family Medicine and Community Health, Duke School of Medicine, Durham, North Carolina.

References

1. Hanson P. Citizen involvement in community health promotion: a role application of CDC's PATCH model. *Int Q Community Health Educ*. 1988;9(3):177–186. doi:10.2190/FMWL-59TW-T3CL-VJ16
2. Puska P, Salonen JT, Tuomilehto J, Nissinen A, Kottke TE. Evaluating community-based preventive cardiovascular programs: problems and experiences from the North Karelia project. *J Community Health*. 1983;9(1):49–64. doi:10.1007/BF01318933
3. Centers for Disease Control and Prevention. *Principles of Community Engagement*. 1st ed. CDC/ATSDR Committee on Community Engagement; 1997.
4. US Department of Health and Human Services. *Principles of Community Engagement*. 2nd ed. US Government Printing Office; 2011.
5. Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry. *Principles of Community Engagement*. 3rd ed. Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry; 2025.
6. Association of American Medical Colleges Center for Health Justice. The Centers for Disease Control and Prevention adds a new principle of community engagement. January 21, 2025. Accessed May 8, 2025. https://www.aamchealthjustice.org/news/news/centers-disease-control-and-prevention-adds-new-principle-community-engagement
7. Aguilar-Gaxiola S, Ahmed SM, Anise A, Azzahir A, Baker KE, Cupito A, et al. Assessing meaningful community engagement: a conceptual model to advance health equity through transformed systems for health: organizing committee for assessing meaningful community engagement in health & health care programs & policies. *NAM Perspect*. 2022;2022(2). doi:10.31478/202202c
8. Yuan M, Lin H, Wu H, Yu M, Tu J, Lü Y. Community engagement in public health: a bibliometric mapping of global research. *Arch Public Health*. 2021;79(1):6. doi:10.1186/s13690-021-00525-3
9. Michener JL, Williams A, Oto-Kent D, Aguilar-Gaxiola SA. Community engagement: a foundation for health equity and resilience. *Am J Public Health*. 2025;115(S2):e1–e6.
10. Adsul P, Sanchez-Youngman S, Dickson E, Jacquez B, Kuhlemeier A, Muhammad M, et al. Assessing the context within academic health institutions toward improving equity-based, community and patient-engaged research. *J Clin Transl Sci*. 2024;9(1):e6. doi:10.1017/cts.2024.675
11. Key KD, Furr-Holden D, Lewis EY, Cunningham R, Zimmerman MA, Johnson-Lawrence V, et al. The continuum of community engagement in research: a roadmap for understanding and assessing progress. *Prog Community Health Partnersh*. 2019;13(4):427–434. doi:10.1353/cpr.2019.0064
12. Association of American Medical Colleges Center for Health Justice. The principles of trustworthiness. 2025. Accessed May 18, 2025. https://www.aamchealthjustice.org/our-work/trustworthiness/trustworthiness-toolkit#principles
13. Brewer SE, Nederveld A, Simpson M. Engaging communities in preventing human papillomavirus–related cancers: two boot camp translations, Colorado, 2017–2018. *Prev Chronic Dis*. 2020;17:E02. doi:10.5888/pcd17.190250
14. Olson J, Cawthra T, Beyer K, Frazer D, Ignace L, Maurana C, et al. Community and research perspectives on cancer disparities in Wisconsin. *Prev Chronic Dis*. 2020;17:E122. doi:10.5888/pcd17.200183
15. Payán DD, Derose KP, Flórez KR, Branch CA, Williams MV. The food environment in 3 neighborhoods in South Los Angeles, California: access, availability, quality, and marketing practices. *Prev Chronic Dis*. 2020;17:E61. doi:10.5888/pcd17.200028
16. Thompson JR, Burus T, McAfee C, Stroebel C, Brown M, Francis K, et al. A community-engaged, mixed-methods approach to prioritizing needs in a statewide assessment of community cancer needs. *Prev Chronic Dis*. 2024;21:E103. doi:10.5888/pcd21.240183
17. Keller AO, St. Arnold Bell L, Haglund K. Engaging a community–academic partnership to implement community-driven solutions. *Prev Chronic Dis*. 2025;22:240334.
18. Carnahan LR, Hallock C, Soto B, Kasebier L, Dracos E, Martinez E, et al. Creating and implementing a community engagement strategy for the 2022–2027 Illinois Comprehensive Cancer Control Plan through an academic-state public health department partnership. *Prev Chronic Dis*. 2023;20:E69. doi:10.5888/pcd20.220422
19. DeBruyn L, Fullerton L, Satterfield D, Frank M. Integrating culture and history to promote health and help prevent type 2 diabetes in American Indian/Alaska Native Communities: traditional foods have become a way to talk about health. *Prev Chronic Dis*. 2020;17:E12. doi:10.5888/pcd17.190213

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

20. Elliott JP, Christian SN, Doong K, Hardy HE, Mendez DD, Gary-Webb TL. Pharmacist involvement in addressing public health priorities and community needs: the Allegheny County Racial and Ethnic Approaches to Community Health (REACH) project. *Prev Chronic Dis.* 2021;18:E07. doi:10.5888/pcd18.200490
21. Kepper M, Stamatakis KA, Mudd N, Deitch A, Terhaar A, Liu J, et al. A communitywide collaboration to increase enrollment, retention, and success in evidence-based lifestyle-change programs in racial and ethnic minority populations. *Prev Chronic Dis.* 2023;20:E67. doi:10.5888/pcd20.220352

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 17, E02 JANUARY 2020

RESEARCH BRIEF

Engaging Communities in Preventing Human Papillomavirus-Related Cancers: Two Boot Camp Translations, Colorado, 2017–2018

Sarah E. Brewer, PhD, MPA[1,2]; Anne Nederveld, MD, MPH[1]; Matthew Simpson, MD, MPH[1,2]

Accessible Version: www.cdc.gov/pcd/issues/2020/19_0250.htm

Suggested citation for this article: Brewer SE, Nederveld A, Simpson M. Engaging Communities in Preventing Human Papillomavirus-Related Cancers: Two Boot Camp Translations, Colorado, 2017–2018. Prev Chronic Dis 2020;17:190250. DOI: https://doi.org/10.5888/pcd17.190250.

PEER REVIEWED

Summary

What is already known on this topic?

Despite data on safety and effectiveness, HPV vaccination remains underused. Boot Camp Translation (BCT) is a process for developing messages to improve local uptake of evidence-based practices.

What is added by this report?

BCT was adapted for translation of HPV vaccination evidence to community practice and sample messaging materials are presented.

What are the implications for public health practice?

This project demonstrates the potential of BCT for engaging communities in creating and disseminating message interventions. The BCT process results in locally relevant messages that resonate with communities of diverse populations.

Abstract

Since 2006, a vaccine to prevent human papillomavirus (HPV) infection has been available; however, uptake is suboptimal. To encourage HPV vaccine uptake, we employed Boot Camp Translation (BCT) to develop locally relevant materials in 2 Colorado communities, Mesa County and the Denver metropolitan area (Denver metro). The Mesa County group focused on 2 populations, parents of vaccine-eligible children and young adults. The group identified posters, social media, and educational materials for pediatric primary care settings as venues to deliver their messages. The Denver metro group focused on parents of children with low health literacy. Four messages explain the vaccine and call the selected audience to action. Delivery tactics for that group are social media venues and print education materials, including refrigerator magnets, to remind parents about follow-up dosing. BCT can be adapted to develop locally relevant messages and intervention strategies to address HPV vaccination. Future studies should evaluate the effectiveness of community-derived messages to increase HPV vaccination rates.

Introduction

Human papillomavirus (HPV) causes several types of cancer, including oral and anogenital malignancies, and cancers attributed to HPV are diagnosed in 42,000 people in the United States annually (1). Vaccination against HPV has been available since 2006 for girls and since 2010 for boys. The current vaccine protects against 9 strains of HPV that are responsible for 90% to 95% of anogenital cancers and 95% of genital warts (2). Predictive models indicate that high levels (80%–100%) of adolescent HPV vaccination can result in near eradication of genital warts and substantial (56%–86%) reductions in anal cancer, cervical cancer, abnormal Papanicolaou test results, and HPV-related genital cancers (3). Evidence indicates that HPV vaccination is safe and effective for preventing HPV infection and has no association with significant adverse effects or early onset of sexual activity (4,5).

Despite data on safety and effectiveness, HPV vaccination is underused. US data for 2017 show that 69% of girls and 63% of boys who were eligible (aged 13–17 years) received the first dose, but only 53% of girls and 44% of boys completed the vaccine series (at least 2 doses, depending on age at first dose) by age 17 years (6). In 2018, 72% of eligible adolescents in Colorado had received 1 dose and 54% completed the series (7).

Given persistent low vaccination rates, lack of knowledge, and attitudinal barriers, engaging people in developing community-specific messages that increase knowledge and encourage HPV vaccination might be more effective than using a general approach to increase vaccine uptake. Community-specific messages have the

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

potential to address local concerns more effectively, be more culturally acceptable to selected audiences, increase risk perception, and begin discussions about vaccination.

Boot Camp Translation

Boot Camp Translation (BCT) is a community-engaged translational research process for developing community-specific messages to improve local uptake of evidence-based practices. BCT has been used to develop messages for colon cancer screening, mental health, obesity prevention, diabetes, hypertension, and chronic pain (8,9). The process involves a diverse group of 10 to 12 community members (eg, different professions, racial/ethnic groups, or ages) who learn about the scientific evidence on a health topic and strategize together how to translate that evidence into messages for the local community. BCT begins with a kick-off meeting that includes an expert presentation on the topic to increase participant knowledge of current evidence and ease in discussing the topic. After the presentation, participants brainstorm to extract the essential concepts in current evidence and translate them into the following:

- What do we want people to learn?
- Who should learn this?
- How should we communicate this message?

The group creates a draft of key messages at the end of the kick-off meeting. Soon after the kick-off, a series of telephone and in-person meetings are held to refine messages, develop and design messaging materials, and plan dissemination. Each stage in the process results in a set of messaging products and a plan for dissemination within the community.

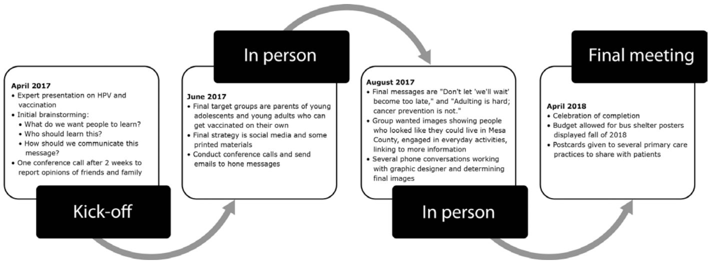
The goal for our project was to apply the BCT process to develop effective community-responsive messages, materials, and dissemination plans to promote HPV vaccination in 2 Colorado communities. We describe the community engagement process and resulting products of the 2 BCTs in this brief. This is the first use of the BCT process to support HPV vaccination and the first BCTs reported in the literature to engage adolescents.

We conducted BCT in 2 Colorado communities, 1 in urban metropolitan Denver (Denver metro) and 1 in semirural Mesa County in western Colorado. The community of Mesa County is composed of the urban Grand Junction and its surrounding rural communities. Approximately 81% of the Mesa County population is non-Hispanic white (10), and 15% of Mesa County residents live in poverty, compared with 11% statewide. At the start of this project, HPV series completion rates were 21% for girls and 16% for boys in Mesa County (7).

In the Denver metro area, we focused on neighborhoods within the catchment area of a partner agency, 2040 Partners for Health. These neighborhoods are racially, ethnically, linguistically, educationally, and economically diverse. For example, in some of these neighborhoods, 50% of residents live below the federal poverty level (≤$25,100 for a family of 4 in 2017) and less than one-half of adults have a high school diploma (11,12). HPV vaccine series completion rates range from 42% to 53% in the counties where these neighborhoods are located (13).

Participation

Eleven participants represented diverse organizations and backgrounds in the Mesa County BCT. Adolescents, parents, health care providers, public health workers, school district employees and social service providers were included in that BCT. Participants were predominantly female and all under retirement age. Ten people participated in Denver metro BCT, including 2 adolescents, 7 parents, and a diverse representation of human service and public health employees. Participants were from different races/ethnicities, languages, and age groups. The group in Mesa County met in person 4 times, including the kick-off. Five 30-minute conference telephone calls were held. The process lasted about 1 year from spring 2017 to spring 2018, somewhat slower than usual because of delays in product design and development. The Denver metro BCT Group also met in person 4 times, including the kick-off. In addition, the group held 7 half-hour conference calls to discuss aspects of message development. The process lasted 6 months, from fall 2017 to spring 2018 (Figure 1).



April 2017
- Expert presentation on HPV and vaccination
- Initial brainstorming:
  - What do we want people to learn?
  - Who should learn this?
  - How should we communicate this message?
- One conference call after 2 weeks to report opinions of friends and family

June 2017
- Final target groups are parents of young adolescents and young adults who can get vaccinated on their own
- Final strategy is social media and some printed materials
- Conduct conference calls and send emails to hone messages

August 2017
- Final messages are "Don't let 'we'll wait' become too late," and "Adulting is hard; cancer prevention is not."
- Group wanted images showing people who looked like they could live in Mesa County, engaged in everyday activities, linking to more information
- Several phone conversations working with graphic designer and determining final images

April 2018
- Celebration of completion
- Budget allowed for bus shelter posters displayed fall of 2018
- Postcards given to several primary care practices to share with patients

Figure 1. Boot Camp Translation activities timeline in Mesa County, Colorado, 2017–2018. Abbreviation: HPV, human papillomavirus.

Messages

In Mesa County, participants decided to develop 2 sets of messages, 1 for parents of children aged 9 to 11 years (preteens) and 1 for young adults (aged 18–26 years) who were not yet vaccinated. They chose to focus on parents of preteens after learning that the vaccine is most effective when administered to children in this age group (14). Participants believed that parents wait to vaccinate for

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

HPV because they perceive risk of HPV infection to be low for their children and do not understand the immunologic benefit of vaccinating early. Key messages that the group wanted to convey were

- HPV causes multiple types of cancer, not just cervical cancer.
- The HPV vaccine is recommended for boys and girls.
- The HPV vaccine is more effective when administered to children aged 9 to 14 years than age 15 years or older.

These concepts resulted in the tagline, "Don't let 'We'll wait' turn into 'too late.'" The tagline is coupled with images of parents, presumably, and their preteen children of both sexes. Information about effectiveness of the vaccine when given to preteens was also included.

For young adults, participants wanted to capitalize on empowerment and the ability to make one's own decisions. Resulting key messages were

- It's not too late to get vaccinated.
- Cancer can happen in young adulthood.
- Self-advocacy and empowerment; vaccination is an adult decision.

The group developed the tagline "Adulting is hard; cancer prevention is not," coupled with images of young adults working, studying, or socializing (Figure 2). Other information in the messages included "HPV causes cancer: cervical, penile, vaginal, oral and anal. Get vaccinated." Messages for parents of preteens and young adults direct readers to the website www.HPVFreeCO.org.

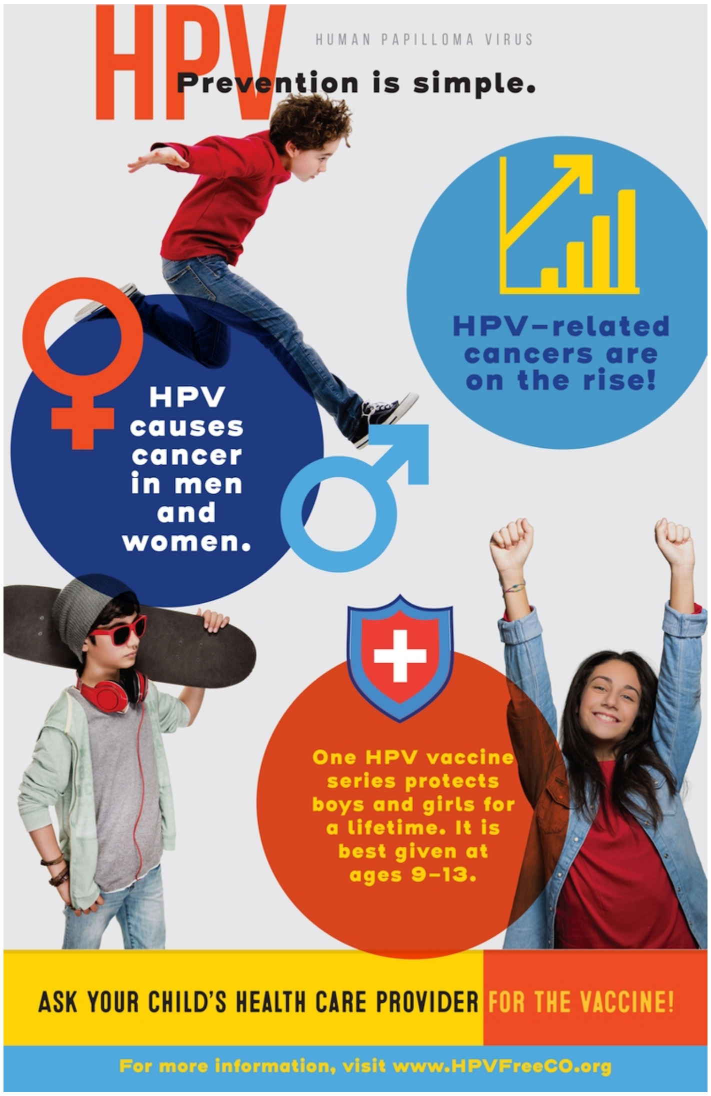


Figure 2. Boot Camp Translation product example for young adults in Mesa County, Colorado.

BCT participants believed social media was an important way to disseminate the messages, particularly for the campaign that focuses on young adults. Images were designed for social media platforms, such as Instagram and Snapchat. This approach would allow for a social media campaign and evaluation of its effectiveness both in messaging and in vaccination rate changes. Postcards, posters, and billboards materials were also developed.

The Denver metro group selected parents of children aged 8 to 13 years with lower health literacy and reduced access to health care and as the target population. The decision to target parents of elementary school children and preteens was motivated by evidence

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

that getting the vaccine before age 15 years is most effective, and by the community's collective knowledge, that access to primary care, including vaccines, is a challenge in Denver metro neighborhoods, as identified by 2040 Partners for Health. Key messages to convey were

- HPV-related cancers are on the rise!
- HPV causes cancer in men and women.
- One HPV vaccine series protects boys and girls for a lifetime and is best administered at ages 9 to13 years.
- Ask your child's health care provider for the vaccine!

The group chose not to develop a tagline; instead, the group integrated messages into an infographic of photographic images and text (Figure 3). The Denver metro campaign also directed readers to the website www.HPVFreeCO.org for more information. However, the group believed it was crucial to provide key information within the messaging, so that it was delivered to readers who did not visit the website.

Figure 3. Boot Camp Translation product example for preteens in Metropolitan Denver, Colorado.

Flyers, web advertisements, and images that fit social media platforms were developed to ensure messages could reach groups through communication tools that were most accessible to them. Postcards, posters, and billboards were created and shared with BCT group members and distributed by the partner organization. At the time of this publication, both Mesa County and Denver metro groups had produced small-scale print campaign products (posters and postcards) for distribution in local venues. Neither the social media campaigns nor the evaluations have been completed in Mesa County or the Denver metro area.

Implications for Public Health Practice

This project demonstrates the potential use of BCT as a method for engaging communities in creating and disseminating message interventions and accompanying dissemination plans that are locally relevant and effective. Our BCT processes in 2 Colorado communities show that BCT can 1) be used to encourage HPV vaccination, and 2) result in locally relevant messages that resonate with communities of unique populations.

Reinforcing the idea that public health messages should be locally generated, discussions after the informational presentation differed between the 2 communities. In Mesa County, participants believed that parent-focused messages should emphasize that the vaccine prevents cancer and encourage vaccination of younger children (ages 9–14 years) because of higher vaccine efficacy at this age. Participants believed that vaccine hesitancy in Mesa County partially stemmed from the understanding of HPV as a sexually transmitted infection that young adolescents would not be exposed to yet. Participants noted the importance of focusing on cancer prevention and removing references to sexual activity. They believed that responsibility for vaccination should be encouraged among young adults as a way to protect themselves against cancers from sexually transmitted infections, and messages should emphasize autonomy and the ability to make one's own health care decisions.

By contrast, in the larger county of Denver, the group determined that the focus should be on misconceptions associated with the HPV vaccine. This group wanted to communicate the long-term prevention effectiveness that the vaccine provides and that a person needs only to receive the vaccine series once. The group decided that parents of elementary school-aged children should hear that the vaccine is best administered early because it is more effective and requires only 2 doses when the series is initiated before age 15 years. This group emphasized 2 barriers to HPV vaccination in their communities. The first barrier is that HPV information for parents is lacking, and the other is that many preteens have insufficient health insurance, resulting in fewer opportunities to see health care providers and get vaccinated. Finally, the Denver metro group wanted to leverage local social connections to distribute the final information and materials from the BCT process. The group agreed that messages would be most effective when delivered by peers in community locations that are frequented by parents, such as recreation centers, churches, food banks, and schools.

Reaching target levels of HPV vaccination rates would be a public health success by greatly reducing morbidity, mortality, and health care costs. Community members are interested in learning

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

more about HPV vaccination and in actively participating in message development for cancer prevention and other important public health topics. Messages developed through processes like BCT, which explores and incorporates community perspectives and voice, can be more accepted and effective than messages developed without community input. The effectiveness of messages developed through community-engaged approaches like BCT should be further explored in the context of vaccination and adolescent health. A small-scale release of the campaign was implemented in both the Denver metro area and in Mesa County. We plan to continue the campaign and evaluate the effectiveness of these locally relevant messages. We also aim to expand the use of the BCT approach to develop messages for HPV vaccination and other adolescent vaccines in more Colorado counties.

Acknowledgments

Sarah Brewer and Anne Nederveld contributed equally to this article and are co-first authors. This project was supported by ACS Institutional Research Grant no. 16-184-56 from the American Cancer Society. We extend an enormous thanks to our community partners in the Denver metro area and Mesa County, Colorado, without whom this process could not have happened. No copyrighted materials were used in the preparation of this article.

Author Information

Corresponding Author: Sarah E. Brewer, PhD, MPA, Department of Family Medicine, University of Colorado Anschutz Medical Campus, Mail Stop F443, 13199 E Montview Blvd, Suite 300, Aurora, CO 80045. Telephone: 303-724-6927. Email: Sarah.Brewer@cuanschutz.edu.

Author Affiliations: [1]Department of Family Medicine, University of Colorado Anschutz Medical Campus, Aurora, Colorado. [2]Adult and Child Consortium for Health Outcomes Research and Delivery Science (ACCORDS), University of Colorado Anschutz Medical Campus, Aurora, Colorado.

References

1. Centers for Disease Control and Prevention. How many cancers are linked with HPV each year? https://www.cdc.gov/cancer/hpv/statistics/cases.htm. Published 2018. Accessed April 26, 2019.
2. Pitisuttithum P, Velicer C, Luxembourg A. 9-Valent HPV vaccine for cancers, pre-cancers and genital warts related to HPV. Expert Rev Vaccines 2015;14(11):1405–19.
3. Van de Velde N, Boily MC, Drolet M, Franco EL, Mayrand MH, Kliewer EV, et al. Population-level impact of the bivalent, quadrivalent, and nonavalent human papillomavirus vaccines: a model-based analysis. J Natl Cancer Inst 2012;104(22):1712–23.
4. St Laurent J, Luckett R, Feldman S. HPV vaccination and the effects on rates of HPV-related cancers. Curr Probl Cancer 2018;42(5):493–506. .
5. Kasting ML, Shapiro GK, Rosberger Z, Kahn JA, Zimet GD. Tempest in a teapot: a systematic review of HPV vaccination and risk compensation research. Hum Vaccin Immunother 2016;12(6):1435–50. .
6. Walker TY, Elam-Evans LD, Yankey D, Markowitz LE, Williams CL, Mbaeyi SA, et al. National, regional, state, and selected local area vaccination coverage among adolescents aged 13-17 years — United States, 2017. MMWR Morb Mortal Wkly Rep 2018;67(33):909–17. .
7. Colorado Department of Public Health and Environment. CIIS county level rates. https://www.colorado.gov/pacific/cdphe/ciiscountylevel. Published 2019. Updated 2019. Accessed October 3, 2019.
8. Norman N, Bennett C, Cowart S, Felzien M, Flores M, Flores R, et al. Boot camp translation: a method for building a community of solution. J Am Board Fam Med 2013;26(3):254–63. .
9. Westfall JM, Zittleman L, Felzien M, Norman N, Tamez M, Backlund-Jarquin P, et al. Reinventing the wheel of medical evidence: how the boot camp translation process is making gains. Health Aff (Millwood) 2016;35(4):613–8. .
10. US Census Bureau. QuickFacts — Mesa County, Colorado. https://www.census.gov/quickfacts/mesacountycolorado. Accessed November 20, 2019.
11. Denver Human Rights and Community Partnerships, Office of Community Support. Denver immigrant community and neighborhood assessment. https://www.denvergov.org/content/dam/denvergov/Portals/643/documents/Offices/Office%20of%20Immigrant%20and%20Refugee%20Affairs/ImmRefAssessment.pdf. Accessed November 20, 2019.
12. Tri-County Health Department. 2018 Community health assessment. https://www.tchd.org/DocumentCenter/View/5134/TCHD_Community-Health-Assessment-2018. Accessed August 30, 2018.
13. Colorado Department of Public Health and Environment. Colorado Health Indicators 2019. https://www.colorado.gov/pacific/cdphe/colorado-health-indicators. Accessed May 24, 2019.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

14. Iversen OE, Miranda MJ, Ulied A, Soerdal T, Lazarus E, Chokephaibulkit K, et al. Immunogenicity of the 9-valent HPV vaccine using 2-dose regimens in girls and boys vs a 3-dose regimen in women. JAMA 2016;316(22):2411–21.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 17, E122 OCTOBER 2020

ORIGINAL RESEARCH

Community and Research Perspectives on Cancer Disparities in Wisconsin

Jessica Olson, PhD, MPH[1]; Tobi Cawthra, MPH[1]; Kirsten Beyer, PhD, MPH, MS[1]; David Frazer, MPH[2]; Lyle Ignace, MD[3]; Cheryl Maurana, PhD[1]; Sandra Millon-Underwood, RN, PhD, FAAN[4]; Laura Pinsoneault, PhD[5]; Jose Salazar, BS[6]; Alonzo Walker, MD[1]; Carol Williams, PhD[1]; Melinda Stolley, PhD[1]

Accessible Version: www.cdc.gov/pcd/issues/2020/20_0183.htm

Suggested citation for this article: Olson J, Cawthra T, Beyer K, Frazer D, Ignace L, Maurana C, et al. Community and Research Perspectives on Cancer Disparities in Wisconsin. Prev Chronic Dis 2020;17:200183. DOI: https://doi.org/10.5888/pcd17.200183.

PEER REVIEWED

SUMMARY

What is already known about this subject?

Listening sessions and interviews with community and research groups provided unique insight into factors that contribute to cancer disparities, barriers to improving outcomes, and opportunities to improve health.

What is added by this report?

Analyzing data through The Model for Analysis of Population Health and Health Disparities contributed to our understanding of how different groups understand factors associated with disparities and where opportunities for meaningful collaboration exist.

What are the implications for public health practice?

The model allowed us to more fully understand the importance of seeking solutions to cancer disparities through a multisector approach rooted in the specific needs of communities.

Abstract

Introduction

Significant disparities are apparent in geographic areas and among racial/ethnic minority groups in Wisconsin. Cancer disparities are complex and multifactorial and require collaborative, multilevel efforts to reduce their impact. Our objective was to understand cancer disparities and identify opportunities to collaborate across community and research sectors to address them.

Methods

From May 2017 through October 2018, we assembled groups of community members and researchers and conducted 10 listening sessions and 29 interviews with a total of 205 participants from diverse backgrounds. Listening sessions and interviews were scheduled on the basis of participant preference and consisted of a brief review of maps illustrating the breast and lung cancer burden across Wisconsin, and a semistructured set of questions regarding causes, solutions, and opportunities. Interviews followed the same structure as listening sessions, but were conducted between a facilitator and 1 or 2 individuals. Major themes were summarized from all sessions and coded. We used the Model for Analysis of Population Health and Health Disparities to identify areas for collaboration and to highlight differences in emphasis between community participants and researchers.

Results

Participants identified the need to address individual behavioral risks and medical mistrust and to build equitable multilevel partnerships. Communities provided insights on the impact of environment and location on cancer disparities. Researchers shared thoughts about societal poverty and policy issues, biologic responses, genetic predisposition, and the mechanistic influence of lifestyle factors on cancer incidence and mortality.

Conclusion

Listening sessions and interviews provided insight into contributors to cancer disparities, barriers to improving outcomes, and opportunities to improve health. The unique perspectives of each group underscored the need for multisector teams to tackle the complex issue of cancer disparities.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

Introduction

Cancer incidence and mortality in the United States have decreased overall in recent years, but not equally across all populations. Disparities may be related to race, ethnicity, socioeconomic status, and geographic location, and their underlying causes are complex and multifactorial (1–3). An interplay of biology, individual behavior, socioeconomic status, social conditions, social norms, and environment contribute to disparities in cancer incidence, late-stage diagnosis, and mortality (4–5). In Wisconsin, where cancer is a leading cause of death, significant disparities are apparent in geographic areas and among racial/ethnic minority groups (6–9). Wisconsin has the nation's second largest Black–White disparity in lung cancer mortality, and the Milwaukee metropolitan area has the largest Black–White disparity in lung cancer mortality among metropolitan areas nationwide (rate ratio = 1.635). Additionally, Wisconsin has the nation's third largest Black–White disparity in female breast cancer mortality (rate ratio = 1.600) (6,9).

Recognizing the impact lung cancer and female breast cancer have in Wisconsin, the Advancing a Healthier Wisconsin Endowment committed a substantial investment to reduce breast and lung cancer disparities (10). The endowment sought an innovative solution that leveraged the strengths of community-based organizations, population health, and basic science. As a first step, the endowment convened a design team of 10 representatives from research and community settings. The team's objective was to engage people from different disciplines and communities with varied perspectives on the causes of breast and lung cancer disparities and to inform effective strategies to collaborate across these sectors. To achieve this, the design team conducted statewide focus groups with diverse participants. Team members recommended calling the groups "listening sessions" because facilitators were there to listen, not examine as in a focus group. We describe the listening-session approach and key findings from the sessions.

Methods

Recruitment

The design team (authors J.O., T.C., K.B., D.F., L.I., S.M., L.P., J.S., A.W., C.W., M.S.) met regularly from March 2017 to October 2018 and used publicly available maps to identify areas of Wisconsin where lung and female breast cancer rates were higher than expected and where rates of the 2 cancers differed from each other (Figure 1) (11). Nine counties of interest were identified on the basis of apparent disparities in breast and lung cancer incidence and mortality. We contacted public health directors from each county department of health by email to explore their interest in organizing listening sessions and interviews. We sent a follow-up email, followed by a telephone call, to directors who did not respond to the initial email. Of the 9 counties, 7 directors expressed interest, and their counties were included: Marinette, Milwaukee, Oconto, Racine, Vilas, Oneida, and Walworth. The county communities were diverse in their populations' racial/ethnic make-up and other socioeconomic indicators (Table 1).

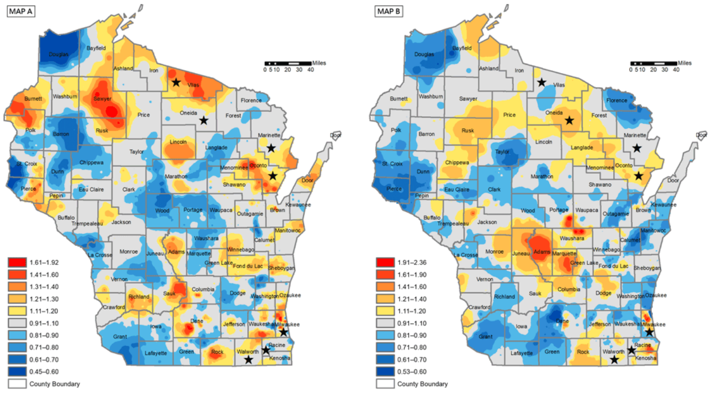


Figure 1. Female breast cancer mortality rate (Map A) and lung cancer mortality rate (Map B), Wisconsin, 2008–2013. The female breast cancer mortality rate is indirectly age standardized and smoothed using adaptive spatial filtering. The lung cancer mortality rate is indirectly age–sex standardized and smoothed using adaptive spatial filtering. A grid of points is used to estimate mortality rates continuously across the map, based on the 20 closest breast cancer deaths and the 40 closest lung cancer deaths. Red areas indicate higher rates than expected and blue areas indicate lower rates than expected, compared with the regional rate. Areas without color indicate rates close to the regional rate. Data source: State Vital Records Office, Wisconsin Department of Health Services 2008-2013 (12). Reprinted with permission of Yuhong Zhou, PhD, and Kirsten Beyer, PhD, MPH, MS, Medical College of Wisconsin.

A total of 205 people participated in either listening sessions or interviews from May 2017 through October 2018. To represent the biomedical science groups (bench, clinical, and population health researchers), we invited 50 researchers from Wisconsin and 26 researchers at a national conference. Forty-seven Wisconsin researchers and 20 national researchers accepted. All participants in the biomedical science groups had expertise in cancer and/or disparities research. For this group, 5 sessions were held with a maximum of 11 participants each. In community groups, public health directors who expressed interest in hosting listening sessions invited members of their community that they believed would have insight on cancer incidence in their community. Community participants were leaders from community and nonprofit organizations, community health workers, nonaffiliated community members, directors of federally qualified health centers and free clinics, and public health professionals. We conducted 5 listening sessions (participant number determined by public health director) and 29 interviews (1–2 participants per session) with community groups.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

We also conducted a listening session at a statewide meeting of Wisconsin's Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program. For all participants, participating in a listening session or interview was determined by the participant's preference and availability.

Listening sessions and interviews

Our multidisciplinary team of community members and researchers conducted 10 listening sessions and 29 interviews with a total of 205 individuals from diverse backgrounds. We developed a format for successful engagement across diverse groups of communities and researchers (Table 2). All listening sessions and interviews were conducted by design team members (authors T.C., J.O., M.S., K.B., C.W.) or trained facilitators with cancer disparities knowledge, public health expertise, and qualitative data collection experience. Listening sessions and interviews were not audio- or video-recorded because public health officials said that participants would engage more freely if not being recorded. A team member took detailed notes on session content and documented observations related to participant affect or interactions at all interviews and listening sessions. Because sessions were not audio- or video-recorded, documenting body language and behavior added context for qualitative analysis. Following each interview or listening session, the notetaker prepared de-identified summaries, and participants were given the opportunity to review them for completeness and accuracy.

Interviews were scheduled for 60 minutes and listening sessions for 90 minutes. Questions and probes were determined a priori by the design team to capture research and community perspectives on causes and challenges contributing to breast and lung cancer disparities statewide and opportunities to improve health outcomes. To ensure that the verbiage of questions would be understood across community and research populations, the design team tested the applicability of questions across diverse groups with peers and social networks and used their feedback to inform revisions. At listening sessions, the facilitator encouraged participants to openly share their perceptions of their home community, communities statewide, and the environment of cancer research. Participants then examined statewide maps of breast and lung cancer incidence and mortality and discussed whether what they saw in the maps validated or opposed their previous thoughts about community health and cancer disparities. At the end of the listening sessions and interviews, participants were encouraged to ask questions about future directions and were informed of ways to stay connected to the study.

Data analysis

Two trained researchers (T.C., J.O.) coded summaries and observational notes using ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH). In the first round of coding, researchers used open coding to identify themes, key concepts, ideas, beliefs, or events. Researchers met frequently to compare and modify codes and resolve discrepancies through discussion or consultation with a third reviewer. After completing open coding of themes (Table 2), the themes that emerged strongly aligned with The Model for Analysis of Population Health and Health Disparities, a model that illustrates multilevel contributors to cancer disparities, including individual behavior and risk, context, and population factors (13). A second round of coding was then conducted to help identify thematic similarities and differences between researchers and community members to inform opportunities for collaboration or identify experiential gaps that might require further attention (Table 3). All procedures were reviewed and approved by the Medical College of Wisconsin's institutional review board.

Results

Interviews and listening session participants

Listening session and interview participants totaled 205. Twenty-nine interviews were conducted across Wisconsin counties (Marinette, 10 interviews; Oconto, 6; Racine, 7; and Walworth, 6) and consisted of either 1 or 2 participants per interview for a total of 35 people interviewed and 170 participants in listening sessions (Figure 2).

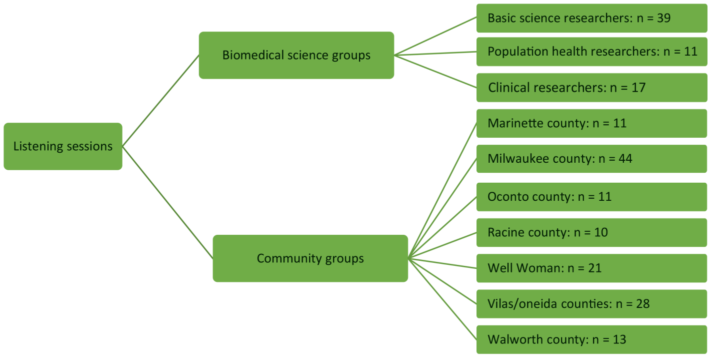


Figure 2. Composition of listening sessions and interviews. A total of 205 participants answered semistructured questions about communities and cancer disparities in Wisconsin. Sixty-seven participants represented basic, population health, and clinical research, and 138 participants represented community perspectives. We also conducted a listening session at a coordinators meeting of Well Woman, the Wisconsin's Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program.

Open coding revealed a broad range of contributors to cancer disparities: biologic contributors, research needs, behaviors and comorbidities, demographic factors, geographic location, environment, social conditions, institutional barriers, and policy issues (Table 2).

Biologic contributors. All sessions acknowledged genetic predisposition for cancer. Modifiable risk factors were believed to be the predominant contributors to cancer disparities, but researchers recognized that some communities were possibly more likely than others to experience geographic disparities through rural isolation and small community size and therefore inherit cancer-causing genes disproportionately.

Research needs. Researchers acknowledged difficulties in recruiting diverse populations for sample collection and clinical trials. One researcher said she had diverse racial and ethnic participation when she began recruitment for a clinical trial, but by the end, “all of the non-White participants had dropped out,” and she had no idea why. Another basic scientist said he was “aware of disparities in cancer incidence” within the type of cancer he studied but was unsure about how to incorporate that into his animal-based research.

Behaviors and comorbidities. All listening sessions discussed the considerable impact of smoking, stress, diet, and lack of physical activity on rates of cancer incidence and mortality. Researchers also discussed the impact of reproductive factors, such as parity, breastfeeding practices, and the use of hormone replacement therapy on breast cancer. Community participants had specific ideas to improve health outcomes that would address local concerns. For example, in one rural area of Wisconsin with high levels of summer tourism, community members said that walking paths in the area would be used by local residents much more often if the paths actually went places (like the grocery store), instead of in circles (for the tourists). Another community participant said that a great opportunity to conduct an intervention would be at “thresherees,” which are gatherings of local agricultural community members during harvest seasons.

Demographic factors. Community health care providers said that many of their current research efforts focused on educating communities and increasing knowledge and awareness of cancer-causing agents. In 5 of the 7 counties visited, health care providers shared that adults in their area were aware that they should eat better, be more active, and either eliminate or reduce tobacco and alcohol consumption, yet had little interest in modifying behavior.

Geographic location. Both community participants and researchers discussed the influence of distance and travel time on health care, but these were not the sole concerns related to access. In 2 separate listening sessions, participants said that they would “have to be dying” to seek care at their local health care facility and would prefer to drive an hour or more to larger cities for what they trusted to be better quality care. In urban settings, mistrust stemmed from experiences and beliefs that care would be delivered differently because of the race, ethnicity, or socioeconomic status of the patient. Researchers and public health experts discussed this mistrust but did not acknowledge its nuances in different demographic groups.

Environment. Community participants expressed concerns about airborne, housing, and workplace exposures to harsh chemicals and environmental pollutants, which differed by region. In northern Wisconsin, industrial chemicals found in paper mills and mining were mentioned, and in agricultural areas throughout the state, exposure to pesticides and herbicides were referenced as concerns. Participants from urban areas expressed more concern about pollution and quality of housing. Researchers acknowledged the impact of the environment on health and were knowledgeable about the high levels of radon in certain Wisconsin communities, but did not focus discussions on any other community-specific exposures.

Social conditions. Population health researchers and community participants shared that a significant disparity between communities exists in the way that tobacco and alcohol are promoted. Sale of tobacco and alcohol is promoted in areas where racial/ethnic and sex and gender minority groups reside, whereas health care, healthy foods, and healthy behaviors are promoted more in suburban, affluent areas with predominantly White populations. In rural communities, participants said, “everybody smokes” and “everybody drinks.” A public health professional said in an interview that tobacco use was so prevalent that when young women become pregnant, they merely switched from cigarettes to chewing tobacco for the duration of their pregnancy. Participants from communities across Wisconsin said that alcohol is expected at all social gatherings.

Institutional barriers. All participants acknowledged the institutional challenges to reducing cancer disparities. Researchers cited challenges in obtaining funding, building new partnerships, and then sustaining connections when funding runs out. In communities, institutional barriers were centered around the limited time or resources to form new partnerships and launch programs and the shortage of physicians in an area. A rural nurse practitioner shared that many community members were unwilling (because of perceptions) or unable (for insurance reasons) to receive care from nurse practitioners or health professionals with nonterminal degrees.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

Policy issues. Listening sessions revealed issues with insurance and generic drug costs, societal poverty, and challenges in banning carcinogenic substances. In multiple listening sessions in northern Wisconsin, community participants said that despite the presence of a statewide indoor smoking ban, smoking was still prevalent in taverns, restaurants, and other public places. Community groups discussed agricultural pesticide use and said that determination of which chemicals are allowed is based on their cost and farmers' preference without consideration for the health of community members.

By using the Model for Population Health and Health Disparities as a framework to compare research and community perspectives, we were able to compare areas of emphasis between groups. The model served as a powerful tool to identify areas with shared knowledge for future multisector collaboration (Table 2) and areas where more education was likely needed (Table 3).

Areas with shared knowledge. Areas with shared knowledge indicated topics with potential for rapid, multisector collaboration. For example, all participant groups discussed the contribution of individual risk factors to cancer disparities but had different expertise and interests in the topics discussed. Alcohol consumption was identified as a contributing factor to cancer across groups, and basic science researchers focused on understanding cellular and molecular mechanisms and discussed work being conducted by local experts that could be focused on state-level issues (14). Population health researchers focused on frameworks that drive lifestyle choices, such as the Transtheoretical Model, and successful interventions to improve health outcomes (15,16). Community participants focused on the social and cultural norms specific to their area.

Areas with differences in emphasis between participant groups. Areas where emphasis differed between groups showed that more education would likely be needed to create multisector teams. For example, basic science researchers focused heavily on the mechanisms of DNA and cellular damage and protective factors that need to be better understood. Only researchers mentioned how reproductive and gynecologic factors such as breastfeeding practices, parity (having borne children), and the use of hormone replacement therapy were factors in breast cancer incidence. Community participants had unique insights regarding the physical context of cancer disparities, that is, how the environment and location affect health outcomes. They went into detail about specific agricultural, industrial, workplace, and home exposures that may affect health. For example, in Northern Wisconsin, heavy snowfall can block roads and prevent trucks from delivering propane to heat homes throughout winter and into April and May. To compensate for this, some residents switch to burning wood as a heat source. Wood smoke is a source of benzene, defined as a carcinogen by the International Agency of Research on Cancer. However, limited research has examined the correlation between home heating with open fires or closed burners and cancer incidence (17). Although researchers discussed how social context in general contributes to cancer disparities, community participants had extensive knowledge about the complex, community-specific interplay of social relationships, social conditions, and policy.

Use of maps to stimulate discussion

We found use of maps to be a critical factor in our investigation. Although both community and research groups tended to focus on the maps or the specific geographic elements where disparities were high, the maps were useful in helping participants go beyond their initial thoughts on factors influencing disparities. As a result of sharing maps, researchers who were previously unaware of cancer disparities were eager to learn more and share access to research equipment (such as next generation imaging and sequencing technology), collaborators, and expertise. Community participants in urban areas were largely aware of cancer disparities, but seeing the warm or hot colors on the maps illustrating the additional burden in their region resulted in comments of interest, dismay, confusion, and commitment ("we need to do something about this"). In rural communities, where initial conversations focused on the fresh air, outdoor activities, and environment that are healthier than that of urban settings, participants were surprised by the maps. Seeing the warm or hot colors on their rural regions on the map indicating high cancer incidence and mortality shifted the discussion to possible causes, such as industrial and agricultural exposures, cultural norms, and health care quality.

Discussion

The US Department of Health and Human Services called for the elimination of health disparities and achievement of health equity in Healthy People 2020 (4). Our statewide listening sessions and interviews with community members and researchers uncovered multisector factors that contribute to disparities. Previous studies used this listening session approach to uncover barriers between community and science that need to be addressed to reduce health disparities, such as cultural humility and skepticism and mistrust about research (18,19). In our study, we sought to understand the differences in emphasis that diverse participants in research and community settings would place on causes of cancer disparities. When we used disparities-based frameworks in different settings (such as research vs community settings), focus on aspects of the Model for Analysis of Population Health and Health Disparities (13) shifted. This is likely a major reason that disparities are difficult to address. It is challenging for participants to draw their focus from what is most salient to them and examine broader per-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

spectives. We found that each group offered a unique perspective based on their expertise and experience and acknowledged that other sectors also needed to make a significant impact to reduce cancer disparities. Across communities, there was a shared desire to improve health outcomes, and multiple suggestions were offered as first steps. All groups wanted to reduce disparities and improve health outcomes and identified the following 3 key issues to address.

Major contributors to cancer disparities are complex and vary between regions and communities. The root causes of cancer disparities are complex and multifactorial. Eliminating cancer disparities statewide requires consideration of the unique factors among communities that underlie disparities. Our statewide listening sessions revealed isolated incidents of environmental contamination, deeply ingrained cultural norms, and institutional barriers that all need to be acknowledged. Nationwide, it is clear that a one-size-fits-all approach across diverse community settings is not sufficient. Previous studies have demonstrated that risk factors contributing to mortality and prognoses differ between races and geographic locations (20,21). The Model for Analysis of Population Health and Health Disparities (13) illustrates the impact of many proximal, distal, and intermediate factors on health. When examining the contributors to health disparities outlined in our listening sessions, factors from each category of this framework emerged (Table 3). Unlike smaller studies that highlighted a central focus for interventions, statewide efforts require interventions that can be tailored to the cultural and geographic needs of the communities affected by cancer disparities (18,19).

Shared knowledge between researchers and community members is needed. Researchers and community groups discussed differing priorities regarding cancer disparities. In our listening sessions, researchers expressed a need for more diverse participation in clinical trials and biospecimen donations. This was a recurrent theme across basic, clinical, and population researcher sessions. Aside from issues of medical mistrust, confusion about the importance of clinical trials is prevalent in communities nationwide, and conceptual frameworks have been created to maximize diverse participation in trials (22–24). In our community listening sessions, clinical trials and biospecimen sample donation were not mentioned. Shared understanding, identification, capacity building, and removal of individual and system-level barriers will be required to bridge the gap between community and research priorities (25–28).

Multisector partnerships are needed to eliminate cancer disparities. Our study showed that broad understanding and appreciation for local social, cultural, and biological influences on cancer disparities is needed in a multisector team setting to achieve health equity in Wisconsin. Efforts are needed to bridge gaps in communication regarding sample donation and disease model development, which basic science researchers valued more than did population health researchers or community members. Basic scientists, conversely, had limited expertise in how social conditions and policy influence health disparities. Given the community and research perspectives on cancer disparities that we observed, educational approaches or guided facilitation will be required to create collaborative efforts. One opportunity to accomplish this would be through the development of training programs that intentionally bring interested participants from biomedical research (basic and population science) and community settings together to learn about each other's worlds and to inform research questions that meet community concerns.

One of our most encouraging findings was the acknowledgment across groups of a need for partnerships, improved training, and patient support. Both researchers and community groups acknowledged that funds and time are limited resources; however, they referenced small coalitions and existing partnerships focused on cancer disparities and population health that have had success in outreach programming or grant funding efforts. Although individuals in all sectors expressed willingness to be a part of a larger collaborative group, partnerships between researchers and community generally do not occur organically. These relationships and interactions need to be fostered and facilitated to ensure equity in influence and outcomes. Although a capacity needs to be built to conduct multidisciplinary, cross-cutting work, research and community-based resources, opportunities, and enthusiasm exist to reduce breast and lung cancer incidence and mortality statewide. Ultimately, our study informed effective strategies for multidisciplinary teams to understand cancer disparities and to collaborate across sectors. This approach is recommended for large- or small-scale initiatives to address complex, multifactorial health issues.

Our study had limitations. The design team did not frame its questions around the Model for Population Health and Health Disparities (13). Also, the absence of discussion of an issue did not necessarily mean an absence of understanding or a lack of desire to address an issue at a research or policy level. Listening sessions were approximately 90 minutes long, and in some groups, discussion was extended around some topics, which limited the amount of time for discussion of other topics. Listening sessions were not taped or transcribed; therefore, our analysis relied on the accuracy of notetaking.

Acknowledgments

The authors gratefully acknowledge Katinka Hooyer, PhD, and the Qualitative Research Consultation Core at the Center for Healthy

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Communities and Research at the Medical College of Wisconsin; Yuhong Zhou, PhD, in the Department of Epidemiology at the Medical College of Wisconsin, for expertise in geospatial mapping; and funding from the Advancing a Healthier Wisconsin Endowment. No copyrighted material was used in this article.

Author Information

Corresponding Author: Jessica Olson, PhD, MPH, Institute for Health & Equity, Medical College of Wisconsin, 8701 Watertown Plank Rd, Milwaukee, WI, 53226. Telephone: 414-955-8656. Email: jeolson@mcw.edu.

Author Affiliations: [1]Medical College of Wisconsin, Milwaukee, Wisconsin. [2]University of Wisconsin-Madison, Madison, Wisconsin. [3]Gerald L. Ignace Indian Health Center, Milwaukee, Wisconsin. [4]University of Wisconsin-Milwaukee, Milwaukee, Wisconsin. [5]Evaluation Plus, LLC, Milwaukee, WI. [6]Sixteenth Street Community Health Centers, Milwaukee Wisconsin.

References

1. American Cancer Society. Cancer facts & figures 2014. Atlanta (GA): American Cancer Society; 2014.
2. Ward EM, Sherman RL, Henley SJ, Jemal A, Siegel DA, Feuer EJ, et al. Annual report to the nation on the status of cancer, featuring cancer in men and women age 20–49 years. J Natl Cancer Inst 2019;111(12):1279–97.
3. Kohler BA, Sherman RL, Howlader N, Jemal A, Ryerson AB, Henry KA, et al. Annual report to the nation on the status of cancer, 1975–2011, featuring incidence of breast cancer subtypes by race/ethnicity, poverty, and state. J Natl Cancer Inst 2015;107(6):djv048.
4. US Department of Health and Human Services. Secretary's Advisory Committee On Health Promotion and Disease Prevention Objectives For 2020. Phase I report: recommendations for the framework and format of Healthy People 2020. https://www.healthypeople.gov/2020/about/advisory/Reports. Accessed July 30, 2020.
5. National Cancer Institute. Cancer disparities. 2019. https://www.cancer.gov/about-cancer/understanding/disparities. Accessed April, 17, 2020.
6. Beyer KMM, Laud PW, Zhou Y, Nattinger AB. Housing discrimination and racial cancer disparities among the 100 largest US metropolitan areas. Cancer 2019;125(21):3818–27.
7. Bemanian A, Cassidy LD, Fraser R, Laud PW, Saeian K, Beyer KMM. Racial disparities of liver cancer mortality in Wisconsin. Cancer Causes Control 2019;30(12):1277–82.
8. Schrager S. Breast cancer: addressing disparities, improving care. WMJ 2018;117(2):52–3.
9. Beyer KM, Zhou Y, Matthews K, Hoormann K, Bemanian A, Laud PW, et al. Breast and colorectal cancer survival disparities in southeastern Wisconsin. WMJ 2016;115(1):17–21.
10. Advancing a Healthier Wisconsin Endowment. Advancing a Healthier Wisconsin, Annual Report 2017. https://ahwendowment.org/AHW1/AnnualReports/2016_2017_Annual_Report.pdf. Accessed May, 20, 2020.
11. Wisconsin Department of Health Services. Vital Records Services. https://www.dhs.wisconsin.gov/vitalrecords/index.htm. Accessed July 30, 2020.
12. Cancer in Eastern Wisconsin. 2020 https://www.mcw.edu/departments/cancer-center/community-outreach-and-engagement/cancer-in-eastern-wisconsin. Accessed April 16, 2020.
13. Warnecke RB, Oh A, Breen N, Gehlert S, Paskett E, Tucker KL, et al. Approaching health disparities from a population perspective: the National Institutes of Health Centers for Population Health and Health Disparities. Am J Public Health 2008;98(9):1608–15.
14. Knight JM, Rizzo JD, Logan BR, Wang T, Arevalo JM, Ma J, et al. Low socioeconomic status, adverse gene expression profiles, and clinical outcomes in hematopoietic stem cell transplant recipients. Clin Cancer Res 2016;22(1):69–78.
15. Prochaska JO, DiClemente CC, Norcross JC. In search of how people change. Applications to addictive behaviors. Am Psychol 1992;47(9):1102–14.
16. Stolley M, Sheean P, Gerber B, Arroyo C, Schiffer L, Banerjee A, et al. Efficacy of a weight loss intervention for African American breast cancer survivors. J Clin Oncol 2017;35(24):2820–8.
17. Bailey HD, de Klerk NH, Fritschi L, Attia J, Daubenton JD, Armstrong BK, et al.; Aus-ALL Consortium. Refuelling of vehicles, the use of wood burners and the risk of acute lymphoblastic leukaemia in childhood. Paediatr Perinat Epidemiol 2011;25(6):528–39.
18. Erves JC, Mayo-Gamble TL, Malin-Fair A, Boyer A, Joosten Y, Vaughn YC, et al. Needs, priorities, and recommendations for engaging underrepresented populations in clinical research: a community perspective. J Community Health 2017;42(3):472–80.
19. Webb Hooper M, Mitchell C, Marshall VJ, Cheatham C, Austin K, Sanders K, et al. Understanding multilevel factors related to urban community trust in healthcare and research. Int J Environ Res Public Health 2019;16(18):E3280.
20. Park J, Blackburn BE, Rowe K, Snyder J, Wan Y, Deshmukh V, et al. Rural-metropolitan disparities in ovarian cancer survival: a statewide population-based study. Ann Epidemiol 2018;28(6):377–84.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

21. Rodriguez EA, Tamariz L, Palacio A, Li H, Sussman DA. Racial disparities in the presentation and treatment of colorectal cancer: a statewide cross-sectional study. J Clin Gastroenterol 2018;52(9):817–20.
22. Trantham LC, Carpenter WR, DiMartino LD, White B, Green M, Teal R, et al. Perceptions of cancer clinical research among African American men in North Carolina. J Natl Med Assoc 2015;107(1):33–41.
23. Barrett NJ, Rodriguez EM, Iachan R, Hyslop T, Ingraham KL, Le GM, et al. Factors associated with biomedical research participation within community-based samples across 3 National Cancer Institute-designated cancer centers. Cancer 2020;126(5):1077–89.
24. Napoles A, Cook E, Ginossar T, Knight KD, Ford ME. Applying a conceptual framework to maximize the participation of diverse populations in cancer clinical trials. Adv Cancer Res 2017;133:77–94.
25. Davis M, Tripathi S, Hughley R, He Q, Bae S, Karanam B, et al. AR negative triple negative or “quadruple negative” breast cancers in African American women have an enriched basal and immune signature. PLoS One 2018;13(6):e0196909.
26. Pérez-Mayoral J, Soto-Salgado M, Shah E, Kittles R, Stern MC, Olivera MI, et al. Association of genetic ancestry with colorectal tumor location in Puerto Rican Latinos. Hum Genomics 2019;13(1):12.
27. Xiao J, Cohen P, Stern MC, Odedina F, Carpten J, Reams R. Mitochondrial biology and prostate cancer ethnic disparity. Carcinogenesis 2018;39(11):1311–9.
28. Reams RR, Kalari KR, Wang H, Odedina FT, Soliman KF, Yates C. Detecting gene–gene interactions in prostate disease in African American men. Infect Agent Cancer 2011;6(Suppl 2):S1.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

Tables

Table 1. Demographic Characteristics, Wisconsin and 7 Participating Counties, Community and Research Perspectives on Cancer Disparities, May 2017–October 2018

Characteristic	Wisconsin	County						
		Marinette	Milwaukee	Oconto	Oneida	Racine	Vilas	Walworth
Population	5,813,434	40,434	948,207	37,830	35,470	196,584	21,938	103,718
Median household income, $	59,209	47,497	48,742	57,105	54,198	59,749	44,285	61,106
Poverty, %	11.0	12.0	19.1	9.2	9.4	12.6	10.9	10.1
Uninsured aged <65 y, %	6.5	6.2	8.1	6.3	6.3	6.2	10.2	8.5
Race/ethnicity, %								
White	81.1	95.1	51.0	94.8	94.7	71.7	84.8	85.3
Black	6.7	0.6	27.2	0.4	0.7	12.0	0.4	1.2
American Indian	1.2	0.8	1.0	1.5	1.2	0.7	11.1	1.1
Hispanic/Latino	6.9	1.9	15.4	1.8	1.6	13.4	2.8	11.2
Female breast cancer 2012–2016								
Age adjusted incidence rate per 100,000[a]	68.0	62.0	74.6	63.4	78.7	69.7	74.0	68.6
Late-stage diagnosis, % of total cases	32.5	37.2	35.6	36.9	37.3	34.4	27.5	32.2
Age adjusted mortality rate per 100,000[a]	10.7	9.8	11.9	11.7	9.8	10.4	10.7	11.0
Lung cancer 2012–2016								
Age adjusted incidence rate per 100,000[a]	59.8	69.8	69.1	64.6	74.6	68.7	72.0	60.0
Late-stage diagnosis, % of total cases	74.3	78.7	77.0	86.0	87.6	74.5	84.3	77.0
Age adjusted mortality rate per 100,000[a]	41.0	48.9	46.6	46.1	48.3	44.9	41.1	45.6

[a] Age adjusted to 2000 US standard population.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table 2. Listening Session and Interview Questions Asked and Participant (N = 205) Characteristics, Community and Research Perspectives on Cancer Disparities, May 2017–October 2018

Listening Session and Interview Format	Justification
Characteristic	
Homogeneous	Create an environment where groups feel comfortable sharing experiences.
Facilitated	Enable open conversation that respects cultural, racial/ethnic, or research identities.
Transparent	Ensure the intentions of data collection are clear, and participants understand their ability to stay informed and continue to give feedback throughout the project.
Valid	Seek feedback from a representative from each community after compilation of data, and make modifications, additions, or redactions before dissemination.
Respectful	Establish at the beginning of each listening session or interview that all opinions are valid, and all participants may finish their thoughts without interruption.
Flexible	Tailor sessions to be responsive to participant needs, including group size, style, language, format, and familiarity with the topic of cancer disparities.
Question	**Probe (if needed)**
Research: How would you describe the health of Wisconsin communities? Community: How would you describe the health of your community?	Research: Rank the health of Wisconsin communities and explain. Community: Rank the health of your community and explain. (A = Excellent, F = Terrible)
If money or resources were no issue, what would you do to improve cancer disparities?	Are there assumptions that people make about (your community/research)?
Why do maps of breast and lung cancer incidence and mortality look the way that they do?	Are there things that surprise you or don't surprise you?
Listening session and interview results, contributors to cancer disparities	**Examples**
Biologic contributors	Genetic predisposition
Research needs	Better cancer detection, availability of samples from different populations, funding
Behaviors and comorbidities	Obesity, poverty, alcoholism, smoking, diet, exercise, stress, reproductive factors, breastfeeding, use of hormone replacement therapy
Demographic factors	Health literacy, gender, race/ethnicity, childhood education
Geographic location	Distance to care, location of care, availability of transportation
Environment	Airborne, housing, and workplace exposures, radon, water quality
Social conditions	Social isolation, cultural norms, social support
Institutional barriers	Availability of quality care, patient support, availability of partnerships and funding sources, medical mistrust
Policy issues	Insurance coverage, societal poverty, generic drug availability, adherence to policy

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table 3. Topics Discussed in Listening Sessions and Interviews, Community and Research Perspectives on Cancer Disparities, May 2017–October 2018[a]

Topic of Discussion	Research Participants		Community Participants (n = 158)
	Basic/Clinical (n = 36)	Population Health (n = 11)	
Biologic and genetic pathways			
Availability of technology, samples, and models	X		
Genetic predisposition	X	X	X
Mechanisms of protection or damage	X		
Biologic responses			
Alcohol, obesity, and stress	X	X	X
Individual risk factors			
Medical mistrust, delay to diagnosis, completion, adherence to care	X	X	X
Reproductive/gynecologic factors	X	X	
Individual diet, alcohol, tobacco, and illegal drug use	X	X	X
Individual demographics			
Access to care		X	X
Childhood and community education		X	X
Cultural and acculturation		X	X
Gender and race	X	X	X
Employment and socioeconomic status		X	X
Physical context			
Environment (agriculture, home, community, workplace exposures)	X	X	X
Location (urban, rural, green, isolated)	X	X	X
Social relationships			
Acceptability of alcohol consumption and smoking	X	X	X
Social factors (support, isolation, pride, self-efficacy)		X	X
Social context			
Effectiveness of partnerships	X	X	X
Social capital	X	X	X
Institutional context			
Adequate patient support, care, and physician training	X	X	X
Capacity for multidisciplinary work	X	X	
Guideline concordant care, hospital volume, cancer detection		X	
Need for champions and funding opportunities	X		X
Social conditions and policy			
Environment, housing, and insurance-based policy		X	X
Insurance issues		X	X
Social inequality and societal poverty	X	X	X

[a] X indicates that the topic was discussed in the basic/clinical research, population health research, and/or community groups.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 17, E61 JULY 2020

GIS SNAPSHOTS

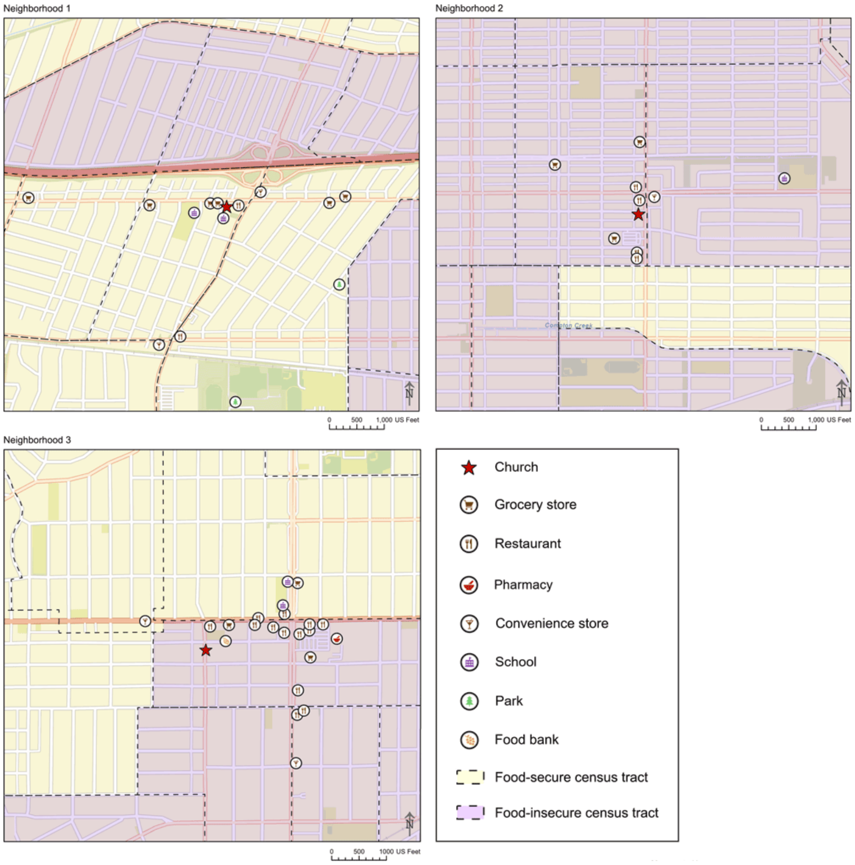
The Food Environment in 3 Neighborhoods in South Los Angeles, California: Access, Availability, Quality, and Marketing Practices

Denise D. Payán, PhD, MPP[1]; Kathryn P. Derose, PhD, MPH[2]; Karen R. Flórez, DrPH, MPH[3]; Cheryl A. Branch, MS[4]; Malcolm V. Williams, PhD, MPP[2]

Accessible Version: www.cdc.gov/pcd/issues/2020/20_0028.htm

Suggested citation for this article: Payán DD, Derose KP, Flórez KR, Branch CA, Williams MV. The Food Environment in 3 Neighborhoods in South Los Angeles, California: Access, Availability, Quality, and Marketing Practices. Prev Chronic Dis 2020; 17:200028. DOI: https://doi.org/10.5888/pcd17.200028.

PEER REVIEWED



Comparison of brick-and-mortar food source types and food-insecure census tracts in 3 low-income neighborhoods in South Los Angeles, California, 2016. A food-insecure census tract was defined as a low-income census tract with ≥500 or ≥33% of residents located more than a half-mile from the nearest supermarket. Map created by Amy Newsam, SpARC Lab, University of California, Merced.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

Data on the food environment can inform strategies to address obesity, particularly in food deserts, defined as low-income neighborhoods with limited access to affordable, nutritious food (1). Such data can empower residents and community-based organizations to identify policy, systems, and environmental strategies to increase access to healthy food and reduce nutrition-related health disparities in their communities (2–4).

We developed a mapping component as part of a multilevel church-based intervention that used community-based participatory research to prevent obesity in African American and Latino churches in South Los Angeles (5,6). We used the Communities of Excellence in Nutrition, Physical Activity, and Obesity Prevention (CX^3) tools, which consist of geographic information system (GIS) mapping and field surveys to assess local nutrition and physical activity environments (3,7). We developed neighborhood maps of local food environments and provided churches with standardized information on food access, availability, quality, and marketing practices.

Methods

Adhering to the CX^3 GIS mapping procedures (3), we identified food sources within a half-mile radius of 3 churches (a large Roman Catholic church with mostly Latino parishioners and 2 mid-size Baptist churches with African American congregants) in South Los Angeles. Food sources were defined as grocery stores, corner stores, convenience stores, pharmacies, ethnic and specialty food stores, food service facilities, emergency food outlets, farmers markets, and mobile vendors. We used state retail data (as of August 2015) and conducted supplementary internet searches (Google, Yelp) to identify inaccuracies in commercial databases (3,4).

Two trained field workers visited all food sources, churches, parks, and schools in 3 neighborhoods (Neighborhood 1, Neighborhood 2, Neighborhood 3) in 2016 to collect data on food availability, quality of produce available in grocery stores and markets, and marketing; store food environment safety and walkability; fast food restaurants and school outdoor marketing environments; food banks and emergency food outlets; alternative food sources; and mobile vending. We observed mobile vendors near schools (ie, mobile vendors located outside of neighborhood schools) on 1 weekday after school dismissal and churches (ie, mobile vendors located outside of churches) 1 weekend after church services. Field workers also observed whether mobile vendors had an up-to-date permit visible at the point of purchase.

Field workers collected data by using printed CX^3 forms and double-entered data into a computer spreadsheet. We calculated an index of unhealthy-to-healthy food sources for each neighborhood by dividing the number of convenience stores, fast food restaurants, supermarkets, large grocery stores, and small markets not meeting standards by the number of supermarkets, large grocery stores, and small markets meeting standards. Store addresses for brick-and-mortar food sources, schools, and parks were geocoded by using ESRI ArcGIS Pro 2.4.2 (Esri) and reviewed by a GIS researcher. Each map was overlaid with a second layer of census tract data on food insecurity: we defined food-insecure census tracts as tracts in which either ≥500 or ≥33% of residents live at least a half-mile from the nearest supermarket (1).

Highlights

Across the 3 neighborhoods (average population, 11,724 residents), we found 37 brick-and-mortar food sources, 14 emergency and alternative food sources, 5 schools, and 2 parks (Table). The availability of healthy food varied by neighborhood. In Neighborhood 1, 58% (7 of 12) of census tracts were food secure, several supermarkets and small markets met healthy store standards, and the index of unhealthy-to-healthy food sources was 4 (8 to 2). In contrast, 50% (5 of 10) of census tracts were food secure in Neighborhood 3, and only 10% (1 of 10) of tracts were food secure in Neighborhood 2. These neighborhoods had only 1 supermarket or large grocery store each, and each neighborhood had fewer small markets and more restaurants than Neighborhood 1. The index of unhealthy-to-healthy food sources in Neighborhood 2 was 7 (7 to 1), moderately unhealthy. The unhealthiest food environment was Neighborhood 3, which had a high number of unhealthy brick-and-mortar food sources. We were unable to calculate an index in Neighborhood 3 because we found no healthy food sources.

More than half (10 of 18) of food retail stores across all 3 neighborhoods did not sell any fresh fruits or vegetables. In Neighborhood 1, three of 8 stores sold a wide variety of produce, whereas in the other neighborhoods, only 1 store offered a wide variety. Nearly all (6 of 8) brick-and-mortar stores that stocked produce had mostly higher-quality produce; 2 of 8 stores were small markets with moderate or poor-quality produce, located in Neighborhood 2 and Neighborhood 3.

Emergency and alternative healthy food outlets were scarce: we found 1 food pantry in Neighborhood 3 and no farmers market in any neighborhood. In Neighborhood 1, we observed 8 mobile vendors outside churches and 4 mobile vendors outside schools. Of the 8 mobile vendors outside the church in Neighborhood 1, four vendors primarily offered unhealthy food items, and only 1 vendor displayed a permit. All 4 mobile vendors outside schools in Neighborhood 1 and the sole mobile vendor outside a school in Neighborhood 2 offered unhealthy food items; none displayed a permit.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Only 2 of 8 grocery stores met standards for healthy marketing practices in Neighborhood 1, one of 4 grocery stores in Neighborhood 2, and 0 of 6 grocery stores in Neighborhood 3. Subway, a restaurant franchise that primarily sells submarine sandwiches, was the sole restaurant to meet healthy food standards, and each neighborhood had 1 Subway restaurant. Although we observed 17 outdoor advertisements located less than 1,000 feet of a school or park in Neighborhood 1, only 6 advertisements promoted unhealthy items or messages.

Action

Our findings demonstrate the value of mapping food environment data at the neighborhood level to inform community-based strategies to promote healthy eating in low-income neighborhoods. The maps illustrate multiple dimensions of food insecurity — the 3 neighborhoods varied in the availability and quality of healthy food sources and items. Although 1 neighborhood (Neighborhood 1) had moderate access to healthy food, numerous mobile vendors were selling unhealthy food items near its 2 schools and the church participating in our study.

Local food environment maps that are paired with data can inform community-based strategies to prevent obesity and food insecurity. Possible strategies include corner store conversions (8) to increase fresh produce availability and reduce unhealthy food marketing (3). Examining the food environment as part of a faith-based obesity prevention project is important because churches have physical infrastructure, social networks, and other resources that could be leveraged for health promotion and advocacy. Few faith-based obesity interventions target community or policy-level strategies (9). Possible church-based strategies include developing a food pantry in a food-insecure census tract (similar to the food pantry in Neighborhood 3), distributing information on enrollment in nutrition assistance programs, collaborating with mobile food vendors to increase healthy options, and creating church-based gardens for congregants and residents.

The use of CX^3 is a strength of our study because it includes validated instruments for assessing temporary food sources and marketing practices, which are important elements of the food environment but are often excluded from other measures (7,10) and studies (11). Additionally, we collected data on the availability and quality of several foods (4). Supplementary internet searches and in-person visits yielded a comprehensive list of food sources to identify inaccuracies in state data on retail stores (3).

Future studies could train congregants or neighborhood residents to collect and map data to promote community-driven interventions. Additional work should explore how to effectively translate mapping data into policy, systems, and environmental interventions in local contexts.

Acknowledgments

The authors are grateful for the support and participation of Seeds of Hope of the Episcopal Diocese of Los Angeles (Tim Alderson, Steven Trapasso, Erica Nieves, Lindsay Stewart) and Dominic Lathos from the Episcopal Urban Intern Program who contributed to data collection. The authors also acknowledge the contributions of other research staff members (Jennifer Hawes-Dawson, Eunice C. Wong, Margaret Whitley), the California Department of Public Health (Lynn Fuhrman) for providing CX^3 technical support, and members of the Community Steering Committee (especially the Reverend Michael A. Mata, the Reverend Dr Clyde W. Oden, the Reverend Rosalynn Brooks, the Reverend John Cager, the Reverend Walter Contreras, the Reverend Jawane Hilton, Jaime Huerta, the Reverend Martín García, Dr Jan King, the Reverend Felipe Martínez, Bishop Gwendolyn Stone, Nina Vaccaro, and Bishop Craig Worsham). Maps were created by Erin Mutch and Amy Newsam at the University of California, Merced's Spatial Analysis & Research Center (SpARC). No copyrighted materials were used in this study.

Research reported in this publication was supported by the National Institute on Minority Health and Health Disparities of the National Institutes of Health (NIH) (R24MD007943). Dr Payán received salary support during the data collection phase from grant no. T32HS00046 from the Agency for Healthcare Research and Quality (AHRQ). The content is solely the responsibility of the authors and does not represent the official views of the NIH or AHRQ.

Author Information

Corresponding Author: Denise D. Payán, PhD, MPP, Assistant Professor, Department of Public Health, School of Social Sciences, Humanities and Arts, University of California, Merced, 5200 N Lake Rd, Merced, CA 95343. Telephone: 209-228-3618. Email: dpayan@ucmerced.edu.

Author Affiliations: [1]Department of Public Health, School of Social Sciences, Humanities and Arts, University of California, Merced, Merced, California. [2]RAND Corporation, Santa Monica, California. [3]City University of New York, Graduate School of Public Health and Health Policy, New York, New York. [4]Los Angeles Metropolitan Churches, Los Angeles, California.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

References

1. US Department of Agriculture. Food access research atlas: documentation. Washington (DC): Economic Research Service; 2019. https://www.ers.usda.gov/data-products/food-access-research-atlas/documentation. Accessed November 15, 2019.
2. Khan LK, Sobush K, Keener D, Goodman K, Lowry A, Kakietek J, et al.; Centers for Disease Control and Prevention. Recommended community strategies and measurements to prevent obesity in the United States. MMWR Recomm Rep 2009;58(RR-7):1–26.
3. Ghirardelli A, Quinn V, Foerster SB. Using geographic information systems and local food store data in California's low-income neighborhoods to inform community initiatives and resources. Am J Public Health 2010;100(11):2156–62.
4. Gordon-Larsen P. Food availability/convenience and obesity. Adv Nutr 2014;5(6):809–17.
5. Whitley MD, Payán DD, Flórez KR, Williams MV, Wong EC, Branch CA, et al. Feasibility and acceptability of a mobile messaging program within a church-based healthy living intervention for African Americans and Latinos. Health Informatics J 2019:1460458219853408.
6. Derose KP, Williams MV, Flórez KR, Griffin BA, Payán DD, Seelam R, et al. Eat, Pray, Move: a pilot cluster randomized controlled trial of a multilevel church-based intervention to address obesity among African Americans and Latinos. Am J Health Promot 2019;33(4):586–96.
7. Ghirardelli A, Quinn V, Sugerman S. Reliability of a retail food store survey and development of an accompanying retail scoring system to communicate survey findings and identify vendors for healthful food and marketing initiatives. J Nutr Educ Behav 2011;43(4Suppl 2):S104–12.
8. Langellier BA, Garza JR, Prelip ML, Glik D, Brookmeyer R, Ortega AN. Corner store inventories, purchases, and strategies for intervention: a review of the literature. Calif J Health Promot 2013;11(3):1–13.
9. Flórez KR, Payán DD, Palar K, Williams MV, Katic B, Derose KP. Church-based interventions to address obesity among African Americans and Latinos in the United States: a systematic review. Nutr Rev 2020;78(4):304–22.
10. Glanz K, Johnson L, Yaroch AL, Phillips M, Ayala GX, Davis EL. Measures of retail food store environments and sales: review and implications for healthy eating initiatives. J Nutr Educ Behav 2016;48(4):280–8.e1.
11. Walker RE, Keane CR, Burke JG. Disparities and access to healthy food in the United States: a review of food deserts literature. Health Place 2010;16(5):876–84.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table

Table. Availability of Food Source Types, Fresh Fruits and Vegetables, Marketing, and Outdoor Advertising in 3 Low-Income Neighborhoods in Los Angeles, California, 2016[a]

Characteristic	Neighborhood 1	Neighborhood 2	Neighborhood 3	Total
Population	12,470	12,464	10,239	35,173
Population living ≤185% of the federal poverty level, no. (%)	8,106 (65)	6,481 (52)	5,631 (55)	20,218 (57.5)
No. of census tracts, by food-security status				
No. of food-insecure census tracts	5	9	5	19
No. of food-secure census tracts	7	1	5	13
No. of schools	2	1	2	5
No. of parks	2	0	0	2
Brick-and-mortar food sources				
Supermarket chain or large grocery store	2	1	1	4
Small market or other market, including pharmacies	4	2	3	9
Convenience store	2	1	2	5
Fruit-and-vegetable stand	0	0	0	0
Restaurant (including fast food)	2	4	13	19
All	10	8	19	37
Emergency and alternative food source				
Food pantry	0	0	1	1
Mobile vendor (school)[b]	4	1	0	5
Mobile vendor (church)[c]	8	0	0	8
Farmers market	0	0	0	0
All	12	1	1	14
Index of unhealthy-to-healthy food sources[d]	4 (8 to 2)	7 (7 to 1)	(19 to 0)[e]	11.3
Availability and variety of fresh fruit in food retail stores[f]				
None	5 of 8	1 of 4	4 of 6	10 of 18
Limited (1–3 types of fruit)	0 of 8	2 of 4	1 of 6	3 of 18
Moderate (4–6 types of fruit)	0 of 8	0 of 4	0 of 6	0 of 18

[a] State retail data (as of August 2015); internet searches (Google, Yelp), in-person data collection using the Communities of Excellence in Nutrition, Physical Activity, and Obesity Prevention (CX^3) tools; US Department of Agriculture Economic Research Service Food Access Research Atlas, 2010-2015; US Census Bureau, 2010.

[b] Unhealthy food items offered by mobile vendors outside schools were defined as junk food, sugar-sweetened beverages, and ice cream/*paletas*.

[c] Unhealthy food items offered by mobile vendors outside church were defined as fried pork rinds/*chicharrones*, ice cream/*paletas*, bacon-wrapped hot dogs, Mexican-style corn-on-the cob, and chips.

[d] Index of unhealthy-to-healthy food sources was calculated as the number of convenience stores, fast food restaurants, supermarkets, large grocery stores, and small markets not meeting standards divided by the number of supermarkets, large grocery stores, and small markets meeting standards.

[e] Because of a lack of healthy food sources, we could not compute a score.

[f] Supermarket chain or large grocery store; small market or other market, including pharmacies; convenience store (n = 18).

[g] Collected data on marketing materials posted on the exterior (doors and windows) and interior (near check-out area) of each store.

[h] Collected data on marketing materials posted on the exterior and interior of each restaurant and child-oriented marketing practices (eg, photographs of unhealthy food, promotion of kids' meal toy, availability of nutrition information). Restaurants with a marketing score ≥37 (maximum score of 50) were identified as meeting standards for healthy marketing practices.

[i] Includes advertisements for fast food restaurants/fast food meals or sugar-sweetened beverages.

(continued on next page)

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

(continued)

Table. Availability of Food Source Types, Fresh Fruits and Vegetables, Marketing, and Outdoor Advertising in 3 Low-Income Neighborhoods in Los Angeles, California, 2016[a]

Characteristic	Neighborhood 1	Neighborhood 2	Neighborhood 3	Total
Wide (≥7 types of fruit)	3 of 8	1 of 4	1 of 6	5 of 18
Availability and variety of fresh vegetables in food retail stores[f]				
None	5 of 8	1 of 4	4 of 6	10 of 18
Limited (1–3 types of vegetables)	0 of 8	0 of 4	0 of 6	0 of 18
Moderate (4–6 types of vegetables)	0 of 8	2 of 4	1 of 6	3 of 18
Wide (≥7 types of vegetables)	3 of 8	1 of 4	1 of 6	5 of 18
Grocery store marketing practices[g]				
Store meets standards for healthy marketing practices	2 of 8	1 of 4	0 of 6	3 of 18
Restaurant marketing practices[h]				
Restaurant meets standards for healthy marketing practices	1 of 2	1 of 4	1 of 13	3 of 19
No. of outdoor advertisement <1,000 feet of school, park, or playground	17	2	0	19
Presence of advertisement depicting unhealthy items or messages[i]	6 of 17	0 of 2	0	6 of 19

[a] State retail data (as of August 2015); internet searches (Google, Yelp), in-person data collection using the Communities of Excellence in Nutrition, Physical Activity, and Obesity Prevention (CX^3) tools; US Department of Agriculture Economic Research Service Food Access Research Atlas, 2010-2015; US Census Bureau, 2010.

[b] Unhealthy food items offered by mobile vendors outside schools were defined as junk food, sugar-sweetened beverages, and ice cream/*paletas*.

[c] Unhealthy food items offered by mobile vendors outside church were defined as fried pork rinds/*chicharrones*, ice cream/*paletas*, bacon-wrapped hot dogs, Mexican-style corn-on-the cob, and chips.

[d] Index of unhealthy-to-healthy food sources was calculated as the number of convenience stores, fast food restaurants, supermarkets, large grocery stores, and small markets not meeting standards divided by the number of supermarkets, large grocery stores, and small markets meeting standards.

[e] Because of a lack of healthy food sources, we could not compute a score.

[f] Supermarket chain or large grocery store; small market or other market, including pharmacies; convenience store (n = 18).

[g] Collected data on marketing materials posted on the exterior (doors and windows) and interior (near check-out area) of each store.

[h] Collected data on marketing materials posted on the exterior and interior of each restaurant and child-oriented marketing practices (eg, photographs of unhealthy food, promotion of kids' meal toy, availability of nutrition information). Restaurants with a marketing score ≥37 (maximum score of 50) were identified as meeting standards for healthy marketing practices.

[i] Includes advertisements for fast food restaurants/fast food meals or sugar-sweetened beverages.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E103 DECEMBER 2024

ORIGINAL RESEARCH

A Community-Engaged, Mixed-Methods Approach to Prioritizing Needs in a Statewide Assessment of Community Cancer Needs

Jessica R. Thompson, PhD[1,2]; Todd Burus, MAS[1]; Caree McAfee, MA, CHES[1]; Christine Stroebel, MPH[1]; Madeline Brown, MPH[1]; Keeghan Francis, MPH[1]; Melinda Rogers, MA[3]; Jennifer Knight, DrPH[4]; Elaine Russell, MS[5]; Connie Sorrell, MPH[6]; Elizabeth Westbrook, MCHES[6]; Pamela C. Hull, PhD[1,7]

Accessible Version: www.cdc.gov/pcd/issues/2024/24_0183.htm

Suggested citation for this article: Thompson JR, Burus T, McAfee C, Stroebel C, Brown M, Francis K, et al. A Community-Engaged, Mixed-Methods Approach to Prioritizing Needs in a Statewide Assessment of Community Cancer Needs. Prev Chronic Dis 2024;21:240183. DOI: https://doi.org/10.5888/pcd21.240183.

PEER REVIEWED

Summary

What is already known on this topic?

Concept mapping, a participatory approach, is used to assess community health needs. With the nation's highest all-site cancer incidence and mortality, Kentucky residents have a wide range of cancer needs.

What is added by this report?

Through a cancer center–community collaboration, we used a novel online concept mapping approach to capture statewide perspectives from organizational partners and community members to prioritize cancer-related needs in Kentucky.

What are the implications for public health practice?

Our findings indicate the utility of concept mapping to facilitate the prioritization of wide-ranging catchment area needs. The prioritized areas can be used to guide the state's cancer plan and future research to reduce cancer burden.

Abstract

Introduction

Kentucky has the highest all-site cancer incidence and death rate in the US. In 2021, the University of Kentucky Markey Cancer Center convened a steering committee to conduct a statewide community cancer needs assessment (CNA). The goal of the final CNA phase was to gather community input on prioritizing Kentucky's cancer-related needs and ways to address them.

Methods

In 2021, we recruited 162 people to participate in online concept mapping, a participatory mixed method, to explore connections and identify priority areas. Fifty-one community members and 111 organizational partners participated in survey-based activities to prioritize 80 items representing key CNA findings and discussion groups to explore key focus areas and strategies for Kentucky communities.

Results

Concept maps display perceived similarity of the 80 items and a 6-cluster solution. High-priority focus areas included lung cancer screening, smoking, human papillomavirus (HPV) vaccination, and disparities driven by social determinants among rural, Appalachian, Black, and Hispanic residents. High-priority strategies to address needs included expanding health communication on risks, screening guidelines, and insurance benefits; patient navigation; accessible, culturally appropriate treatment information and self-efficacy in treatment decisions; access to care through financial assistance, mobile clinics, and at-home screening; and patient–provider trust and communication.

Conclusion

Our findings indicate the utility of the concept mapping process to facilitate the prioritization of wide-ranging catchment area needs and ways to address them. Moving forward, the prioritized focus areas and strategies can inform Kentucky's new state cancer plan and future research to reduce the state's cancer burden and disparities.

Introduction

Concept mapping is a participatory method used to generate consensus on a specific topic (1,2). This mixed method captures in-depth experiences through qualitative data with the ability to struc-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

ture and prioritize findings for new agendas. Concept mapping has been used to assess community health and cancer-related needs (3,4), including breast cancer screening (5), rural patients with head and neck cancers (6), prostate cancer treatment decisions (7), navigation experiences of breast cancer patients (8), human papillomavirus (HPV) vaccination strategies (9), and cancer survivor needs (10). Over time, online concept mapping tools have added user-friendly elements for direct participation in a web-based platform (11). The need for online options for community-based or qualitative data collection tools increased during the COVID-19 pandemic (12–14). By conducting concept mapping online, the participant pool widens to include broad geographic areas and people who face challenges, such as transportation or childcare, in attending in-person sessions (12).

Promoted by accreditation boards and the Patient Protection and Affordable Care Act, the use of needs assessments among public health agencies, nonprofit hospitals, and state cancer coalitions has grown in recent decades. For example, National Cancer Institute-designated cancer centers are required to regularly assess catchment area needs to develop priorities for health care, research, and cancer control activities (15,16). The University of Kentucky Markey Cancer Center's (UKMCC's) catchment area is the state of Kentucky. With the country's highest all-site cancer incidence and mortality (17), Kentucky residents have a wide range of cancer-related needs across the care continuum from risk reduction to treatment follow-up. The UKMCC Community Outreach and Engagement team convened a steering committee to collaborate on a new cancer needs assessment (CNA). We leveraged online concept mapping as a unique opportunity to capture statewide perspectives from partner organizations and community members to prioritize needs and ways to address them.

To our knowledge, this is the first study by a cancer center–community collaboration to use concept mapping to prioritize cancer needs and strategies. We aimed to 1) identify the range of perceived barriers and facilitators for cancer risk reduction, screening, treatment, and survivorship among Kentuckians; 2) assess the relationships among identified barriers and facilitators based on perceived importance and feasibility to address; and 3) identify data- and community-driven priorities to improve cancer control activities in the state.

Methods

Kentucky CNA

Kentucky maintains an extensive partnership infrastructure to improve cancer prevention and outcomes. Created in 2002 and guided by the UKMCC Community Outreach and Engagement team, the Kentucky Cancer Consortium (KCC) is the state's comprehensive cancer control coalition, which develops and implements Kentucky's cancer plan. The Kentucky Cancer Program (KCP) was founded in 1982 as the state's cancer prevention and control program. KCP-West is led by the University of Louisville, and KCP-East is directed by the University of Kentucky. KCP staff organize and implement evidence-based programs with various local and regional partners.

In 2021, the UKMCC Community Outreach and Engagement team convened a steering committee to drive creation of a new CNA for Kentucky, including statewide organizational partners, clinicians, academics, national foundation representatives, and others engaged in cancer control. Initially, quantitative data used in such assessments were gathered (18–20) to establish current cancer trends and risk factors (16). Additionally, qualitative data, through a series of community focus groups, were collected to understand cancer experiences, perceptions, and needs of Kentuckians. This statewide CNA resulted in a wide range of potential focus areas requiring prioritization for action.

Research design

This study used a mixed-methods, observational design through concept mapping (1,2,4). The concept mapping process involves sequential activities (Figure 1): preparation (Step 1), generation (Step 2), structuring (Step 3), representation (Step 4), interpretation (Step 5), and utilization (Step 6) (2). Data collection typically occurs at 3 points: when brainstorming a list of responses to a focal question (Step 2), when structuring the listed ideas through sorting and rating (Step 3), and when interpreting the generated concept maps and patterns through qualitative group discussions (Step 5).

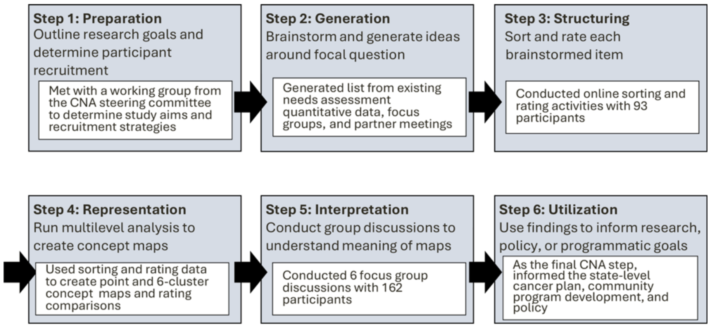


Figure 1. Six steps of concept mapping and project activities. The general steps are indicated at the top of each box, and each inset describes the activity conducted during the project, a cancer needs assessment (CNA) in Kentucky.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Study populations and recruitment

Beginning in September 2021 (Step 1: Preparation), we recruited 2 groups: 1) adult community members who are nonhealth professionals and Kentucky residents and 2) staff of statewide and community-based partner organizations in Kentucky. Due to an active COVID-19 pandemic wave, all recruitment was performed via email. To recruit community members, we contacted 109 people previously screened for the CNA focus groups who had consented to be recontacted for future studies. We initially recruited these people through flyers distributed through the KCP and KCC partnership networks as well as ResearchMatch (21), a national registry of potential research participants. The previously recruited participants had an average age of 49 years, with 35% from rural communities and 31% who identified as a racial or ethnic group other than non-Hispanic White. To recruit statewide and community-based organizational representatives, we invited 186 people from KCC and KCP networks, including health departments, foundations, nonprofit organizations, advocacy groups, health systems, health insurance companies, and educational organizations.

The study team contacted prospective participants via an email invitation, which provided a study cover letter with consent language and a link to the online concept mapping platform. The community member participants received up to $60 in e-gift cards for participation ($30 for the online activities and $30 for the group discussion). The organizational partner representatives participated in their professional roles. All procedures were approved by the University of Kentucky Institutional Review Board as an expedited study with a waiver of consent documentation (no. 73420).

Data collection and analysis

From September through December 2021, we conducted online concept mapping activities using GroupWisdom (11) and Zoom video conferencing (Zoom Video Communications, Inc). Participants could choose to take part in a single activity or all data collection activities. If participants expressed concern about technology during the eligibility screening process, we offered one-on-one sessions for guidance. Additionally, we included study contact information at every concept mapping step to allow participants to raise questions or concerns. We provided regular reminders to maximize participation in each step.

Brainstorming (Step 2: Generation). The authors, a working group of steering committee members, collated data from CNA quantitative data, CNA focus group themes, and common topics raised in KCC and KCP meetings identified through minutes and action items. The use of 3 sources allowed us to triangulate items, to remove duplicates, and to synthesize these items into a single list for use in the subsequent concept mapping activities. The final 80-item list (Appendix) includes topics ranging from health indicators to community and health care obstacles. All 80 items were developed in response to a focal question: "What things, good or bad, impact cancer prevention risk reduction, screening, treatment, or survivorship in Kentucky communities?" We loaded the final list of items into the GroupWisdom online concept mapping platform.

Sorting and rating (Step 3: Structuring). Next, we invited participants to perform sorting and rating activities in the online GroupWisdom platform, which provides detailed instructions to walk participants through each assigned activity. We first asked participants to sort the 80 items into piles they perceived belonged together and to assign a thematic name to each pile. We then asked participants to rate each item on 2 Likert-type scales: 1) How important is this item for Kentucky communities? and 2) How easy would it be to address this item in Kentucky communities? The response choices ranged from 1 (not at all important/not at all easy) to 5 (extremely important/extremely easy). We collected demographic information during this step (age, race, ethnicity, educational attainment, health insurance status, gender identity, LGBTQ+ [lesbian, gay, bisexual, transgender, queer] identity, and family history of cancer).

Quantitative analyses (Step 4: Representation). We used nonmetric multidimensional scaling with the sorting data to create a spatial point map, which uses the relative distances between items to reflect perceived similarities, and hierarchical cluster analysis to depict group consensus on thematic overarching categories in a cluster map; we combined these into a single map (2). Additionally, we examined comparisons for average cluster ratings across the rating scales, including correlational values (*r*). For the highly rated clusters, we created go-zone plots, which use bivariate comparisons to demonstrate which items are highly rated across both scales.

Discussion Groups (Step 5: Interpretation). Finally, in December 2021, we showed the combined point-and-cluster map, rating comparisons, and go-zone plots to participants for interpretation. These sessions followed the structure of a qualitative focus group, where participants reacted to the maps in a semistructured, guided discussion. Overall, we conducted 6 interpretation sessions: 3 with community members and 3 with organizational partners. The community member participants developed the cluster names in breakout rooms based on their perceptions of commonality among the items in each cluster, and a large group discussion ensured consensus among participants. In the organizational partner groups, we discussed prioritization of focus areas for future work in cancer control. During all interpretation sessions, participants were

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

prompted to discuss the clusters most highly rated across both rating scales. We paid special attention to exploring strategies for addressing identified barriers and challenges and observing differences by participant type and geographic area in Kentucky. We recorded the discussion groups and transcribed the recordings, which were used to identify representative quotes.

Results

Overall, 162 people participated in this study. Ninety-three of these people participated in the online sorting and rating activities and answered the demographic questions (Table 1). These online activity participants had a mean age of 50.0 years and were majority non-Hispanic White (82.8%). Approximately 90% of participants identified that they or an immediate family member had a history of cancer, and participants lived in 44 different counties, including 39.3% in rural and 22.5% in Appalachian counties. Our community member participants had greater diversity, including race, ethnicity, education, and insurance type, than the organizational partners.

Cluster maps and names

The best cluster solution resulted in a 6-cluster map, which grouped the 80 items into 6 thematic areas (Figure 2). The cluster names are “Proactive behaviors for improved health” (Cluster 1); “Education, integrative support, and outreach” (Cluster 2); “Equitable accessibility” (Cluster 3); “Perceptions, beliefs, and stigmas” (Cluster 4); “’Kentucky Uglies’: current status of cancer and risk factors” (Cluster 5); and “Disadvantages in Appalachian, Black, and Hispanic communities” (Cluster 6).

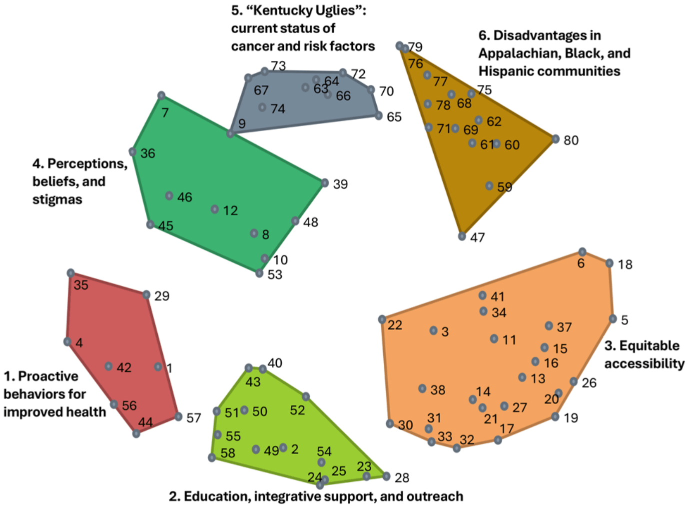


Figure 2. Combined point-and-cluster maps resulting from sorting and rating data. Cluster names were developed by participants in a cancer needs assessment in Kentucky. Relative distances between items reflect perceived similarities.

Topics of focus

Topic areas for partnerships and organizations to address were derived from the cancer risk factors, outcomes, and issues of health equity found in Clusters 5 and 6.

Across Kentucky, items 72 (“About 1 in 4 adults are current smokers, with higher rates in Appalachia [second-highest rate in the US]”) and 62 (“Lung cancer screening rates are low [even worse in the Black community]”) rose to the top among community partners. As one participant described:

> I really like 62 [low lung cancer screening rates] and 72 [high smoking rates], but I would put 62 first because of how difficult it is to try to get people to stop smoking. So at least, if we could move those people toward lung cancer screening, but the thing is, we have to educate the community on who is eligible for lung cancer screening, what it entails, and all of that, but I think that’s a good start.

Participants also identified item 69 (“More Black Kentuckians die from certain cancers than White Kentuckians [examples: uterine, prostate, stomach, myeloma]”) and described the need for continued work addressing disparities in Kentucky’s Black population. For example, prostate cancer:

> One of the things we have continued to promote is prostate screening among African Americans. We have not stopped doing that. We have been doing that for 30 years and as recently as the state fair

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

> this year. So, that's going to remain on our radar because we have funders who want to [do] something and a community who understands there's a need, so that's something we'll continue to do.

Item 65 ("Cancers related to HPV are higher than the US [some of the worst rates in cervical and head/neck cancers]") also regularly arose in conversations, with participants identifying it as a realistic goal. One participant describes: "I think 65 could be really good because that's something we can educate how to prevent and then to really promote the vaccine, and that's one that really is attainable." Finally, items 75 ("Higher levels of poverty among rural, Appalachian, Black, and Hispanic Kentuckians than the US") and 70 ("Higher cancer death rates in counties with lower education versus higher education") commonly emerged, indicating a continued importance for addressing social and economic determinants of health in cancer services.

Additional items were identified by participant type (community members and organizational partners), such as environmental exposures, breast/cervical cancer screening, tobacco use, and physical activity, which may be of interest for the development of cancer services. Likewise, a few items uniquely rose to the top by location of participants in western Kentucky or eastern Kentucky, such as obesity and colorectal screening (Table 2).

Overall, the high levels of commonalities among discussion groups suggest a continued focus on 1) improving rates of smoking and tobacco-related cancers (eg, lung cancer), 2) addressing cancer disparities in Black and Hispanic Kentuckians and in rural and Appalachian communities, 3) understanding the role of social determinants of health (eg, poverty, education), and 4) continuing to expand HPV vaccination and cervical cancer screening.

Strategies for future cancer care efforts

The clusters most highly rated across both rating scales (importance and ease) were "Education, integrative support, and outreach" (Cluster 2) and "Equitable accessibility" (Cluster 3). The go-zone plots for these clusters (Figure 3) have a moderate and weak negative correlation ($r = -0.58$ for Cluster 2 and $r = -0.16$ for Cluster 3), indicating a diversity of thought about the importance and ease across the items in each cluster.

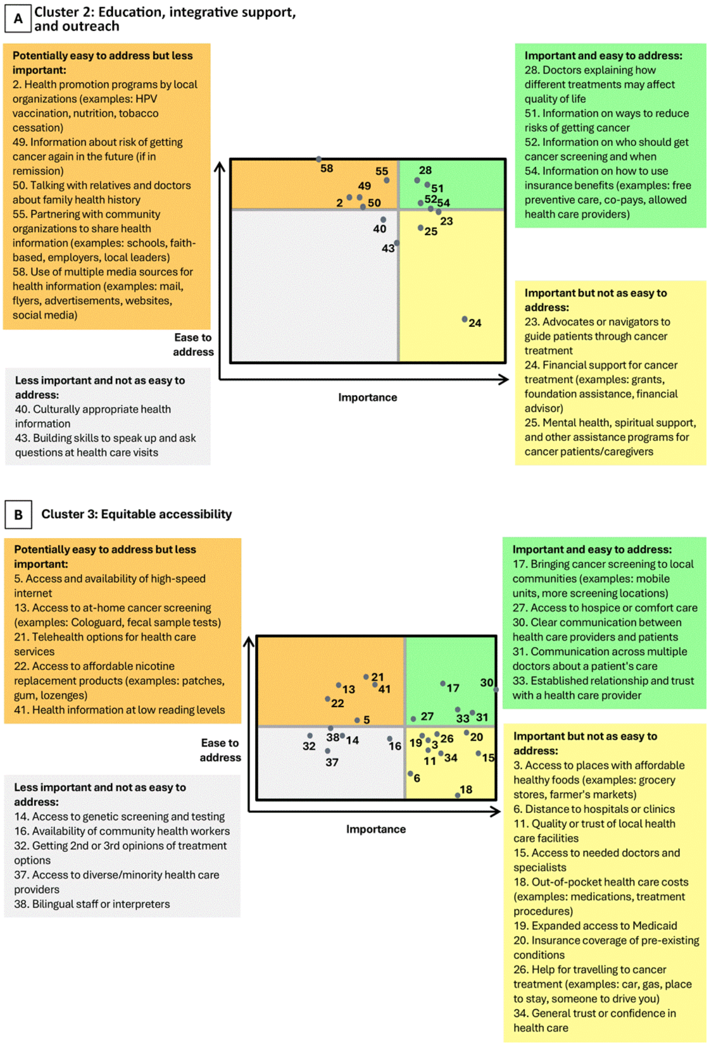


Figure 3. Go-zone plots for A) Cluster 2 (Education, integrative support, and outreach) and B) Cluster 3 (Equitable accessibility). Plots were used to demonstrate items highly rated across scales measuring responses to 2 questions: 1) How important is this item for Kentucky communities? and 2) How easy would it be to address this item in Kentucky communities? Quadrants are sized according to average item ratings. Items with above-average ratings are toward the top (ease to address) or right (importance). Items with below-average ratings are toward the bottom (ease to address) or left (importance).

In Cluster 2, several strategies were raised by both community members and organizational partners, including health communication, particularly around screening information; treatment navigation, including the need for advocates and navigators; and building supports to provide accessible treatment information. For Cluster 3, participants commonly identified items in 2 major categories: access to care, such as ways to reach patients where they are and provide needed supports, and patient–provider trust and/or

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

communication. Participants also highly rated several items as important but not necessarily easy to address, largely around access, insurance, and cost of care. Access to hospice and/or comfort care, partnering with local organizations, quality of local health care facilities, literacy levels, use of media sources, affordable nicotine replacement products, affordable healthy foods, and bilingual staff were strategy-related items uniquely identified by participant type or location (Table 2).

Discussion

Our findings provide evidence for including concept mapping in needs assessments performed by public health agencies, nonprofit hospitals, and state cancer coalitions as well as catchment area assessments conducted by NCI-designated cancer centers. Previous publications on catchment area assessments largely focused on quantitative analyses of secondary data or community-based surveys with few using qualitative approaches (22–25). The inclusion of qualitative data in catchment area assessments captures participant perspectives that may not be reflected in quantitative trends, particularly among underresourced communities (ie, those with high poverty levels, geographic isolation, and/or reduced health care access) (26). Concept mapping adds further depth by generating consensus on an array of needs when resources may dictate the selection of specific action steps.

Concept mapping provides a unique opportunity to capture perspectives from both community members and organizational partners as well as the ability to make comparisons between these groups. Previous concept mapping studies made such comparisons to identify gaps in knowledge or discrepancy of views (3,5,8). In our study, the community member and organizational partner participants largely agreed on the item and cluster ratings for importance and ease to address, which allowed us to show the rating comparisons combined by participant type (eg, Clusters 2 and 3 were the most highly rated for all participants). Additionally, concept mapping, through its combination of individual quantitative activities with qualitative group discussions, allows for the inclusion of all voices, particularly those who may feel less comfortable contributing in a group setting. By including community members and organizational partners in an active way, we gain confidence that our findings will be useful and valid, both for the partners who will be instrumental in developing and implementing cancer risk reduction and control programs and directly for the community.

As with previous applications of concept mapping in health needs assessments (3,4), we found that participants rated all 80 items as important, indicating that community members and organizational partners alike felt that all the cancer needs identified in the CNA required attention. Likewise, our participants recognized the need for continued efforts in addressing the role of social and structural inequities in health outcomes (3). Our results also support previous findings in cancer-related concept mapping projects. For example, various individual (eg, psychosocial factors, financial impacts), social (eg, navigation of personal relationships, social supports [10]), and health care-related factors (eg, desire for health information from providers, access to services (5), empathetic and compassionate communication from providers, participation in one's care decision-making, ways to address fears and anxiety in diagnoses [8]) all emerged in our project. These consistent findings highlight the continued importance of developing strategies related to health communication, compassionate and culturally appropriate ways of sharing information, and the development of continued supports, both financial and social, in cancer care.

Topically, our findings suggest the prioritization of strategies centered on lung cancer risk reduction and screening, including a focus on high smoking rates (Step 6: Utilization). Essential to addressing many forms of cancer, issues of health equity should continue to be a priority, including factors affecting Black and Hispanic Kentuckians and those in rural and low-income communities. Community- and partner-driven strategies to affect these areas include a continued focus on health communication strategies, supports for treatment navigation, ways to overcome barriers to access to care, and methods for increasing trust in patient–provider relationships. Service providers and health care professionals can build on these strategies, which are being included as part of Kentucky's new statewide cancer plan. Since the CNA, the state passed legislation to establish a Kentucky Lung Cancer Screening Program; the bill was signed in July 2022. The findings from this study will inform the activities of this program along with other community cancer risk reduction and control research and services to reduce cancer incidence and mortality in Kentucky.

Limitations

We acknowledge several study limitations. First, because we recruited participants remotely, we may have reached participants with better access to the internet and technology, which may reflect higher levels of geographic access to internet service providers and/or income. However, in previous work, we found that less than 5% of potential participants expressed concerns about online qualitative data collection, and the GroupWisdom platform provides supports for people participating on mobile devices, increasing the likelihood of participation among those without a computer or broadband internet. We also sought to mitigate any digital literacy issues through one-on-one assistance for those who requested guidance and the step-by-step walk-through for each activity provided by GroupWisdom. Additionally, the use of the GroupWisdom platform does require the purchase of a license,

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

which may be cost prohibitive to small community organizations, although nonprofit organizations do qualify for a discount. We observed high participation levels among organizational partner participants who identified as non-Hispanic White, have higher educational attainment, have employer or private insurance, and identify as women, which may reflect the demographic characteristics of the health professions but may not represent the opinions of more diverse populations. Our community member participants consisted of more diverse people and do reflect the overall diversity of Kentucky residents; the 2020 US Census estimates indicate that 38.2% live in rural areas, 26.7% live in Appalachia, and 82.4% identify as non-Hispanic White (27). Although our goal was to broadly capture perspectives across the state, future studies should seek to understand additional viewpoints through the over-recruitment of various racial and ethnic groups, gender identities, and income levels. Likewise, our participants lived in 44 of the 120 Kentucky counties, but their views may not reflect the entire state. Finally, this sample is large for typical concept mapping studies, where sample size is not meant to be generalizable but rather to reach group consensus. As such, our findings are fairly robust and allow for the novel identification of cancer need prioritization in Kentucky.

Conclusion

Overall, our findings indicate the utility of concept mapping for prioritizing wide-ranging catchment area needs uncovered in a CNA. We condensed 80 items into 6 thematic cluster areas for future exploration. Within these clusters, we identified concrete topics for future cancer prevention and control activities, including lung cancer screening, tobacco cessation treatment, and issues of health equity. We also identified community-driven action strategies in Kentucky, such as continuing to improve health communication, patient navigation, access to care, and culturally appropriate health information. As described elsewhere (28), these results provided guidance for overall CNA priorities, including a focus on lung cancer screening, tobacco cessation, and social determinants of health that drive disparities for Black, Hispanic, Appalachian, and rural Kentucky residents. These findings better position the UKMCC Community Outreach and Engagement team and steering committee members to address Kentucky's cancer needs and reduce the state's high cancer incidence and death rates.

Acknowledgments

The authors acknowledge the valuable input of the members of the Kentucky Cancer Needs Assessment Steering Committee and members who represented the Kentucky Cancer Registry (Jaclyn McDowell), Kentucky Cancer Program (Jamie Smith), Kentucky Cabinet for Health and Family Services (Janie Cambron, Vivian Lasley-Bibbs, Emily Messerli, Carissa Adams, Carrie Conia, Elizabeth Owen), American Cancer Society (Elizabeth Holtsclaw, Julie Waters), Foundation for a Healthy Kentucky (Allison Adams), and the University of Louisville (Stephanie Boone). This research was supported by the National Cancer Institute (P30CA177558), the National Center for Advancing Translational Sciences (UL1TR001998), the Centers for Disease Control and Prevention (NU58DP007144 and NU58DP006313), and the William Stamps Farish Endowed Chair in Cancer Research. The authors declare no potential conflicts of interest with respect to the research, authorship, or publication of this article. No copyrighted material, surveys, instruments, or tools were used in the research described in this article.

Author Information

Corresponding Author: Jessica Thompson, PhD, The Pennsylvania State University, 601E Ford Building, University Park, PA 16802 (jrthompson@psu.edu).

Author Affiliations: [1]Community Impact Office, Markey Cancer Center, University of Kentucky, Lexington. [2]Department of Health Policy and Administration, College of Health and Human Development, The Pennsylvania State University, University Park. [3]Kentucky Cancer Program, Community Impact Office, Markey Cancer Center, University of Kentucky, Lexington. [4]Department of Health Management and Policy, College of Public Health, University of Kentucky, Lexington. [5]Kentucky Cancer Consortium, Community Impact Office, Markey Cancer Center, University of Kentucky, Lexington. [6]Kentucky Cancer Program, University of Louisville, Louisville, Kentucky. [7]Department of Behavioral Science, College of Medicine, University of Kentucky, Lexington.

References

1. Burke JG, O'Campo P, Peak GL, Gielen AC, McDonnell KA, Trochim WM. An introduction to concept mapping as a participatory public health research method. *Qual Health Res.* 2005;15(10):1392–1410. doi:10.1177/1049732305278876
2. Kane M, Trochim W. *Concept Mapping for Planning and Evaluation.* Applied Social Research Methods Series. Sage Publications, Ltd; 2007:200.
3. Velonis AJ, Molnar A, Lee-Foon N, Rahim A, Boushel M, O'Campo P. "One program that could improve health in this neighbourhood is ____?" Using concept mapping to engage communities as part of a health and human services needs assessment. *BMC Health Serv Res.* 2018;18(1):150. doi:10.1186/s12913-018-2936-x

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

4. Thompson JR, Burke JG. Increasing community participation in public health research: applications for concept mapping methodology. *Prog Community Health Partnersh*. 2020;14(2):243–250. doi:10.1353/cpr.2020.0025
5. Weinstein LC, LaNoue M, Hurley K, Sifri R, Myers R. Using concept mapping to explore barriers and facilitators to breast cancer screening in formerly homeless women with serious mental illness. *J Health Care Poor Underserved*. 2015;26(3):908–925. doi:10.1353/hpu.2015.0104
6. Foley J, Ward EC, Burns CL, Nund RL, Wishart L, Graham N, et al. Speech pathology service enhancement for people with head and neck cancer living in rural areas: using a concept mapping approach to inform service change. *Head Neck*. 2021;43(11):3504–3521. doi:10.1002/hed.26850
7. McFall SL, Mullen PD, Byrd TL, Cantor SB, Le YC, Torres-Vigil I, et al. Treatment decisions for localized prostate cancer: a concept mapping approach. *Health Expect*. 2015;18(6):2079–2090. doi:10.1111/hex.12175
8. Gallups SF, Demirci J, Nilsen M, Burke J, Bender C, Rosenzweig MQ. Using concept mapping to explore interpersonal communication components of patient navigation in breast cancer care. *Cancer Nurs*. 2023;46(4):321–330.//
9. Askelson N, Ryan G, McRee AL, Farris PE, Shannon J, Hanson J, et al. Using concept mapping to identify opportunities for HPV vaccination efforts: perspectives from the Midwest and West Coast. *Eval Program Plann*. 2021;89:102010. doi:10.1016/j.evalprogplan.2021.102010
10. Hydeman JA, Uwazurike OC, Adeyemi EI, Beaupin LK. Survivorship needs of adolescent and young adult cancer survivors: a concept mapping analysis. *J Cancer Surviv*. 2019;13(1):34–42. doi:10.1007/s11764-018-0725-5
11. Concept Systems Incorporated. GroupWisdom. The groupwisdom™ social research platform is the only tool built for data collection, analysis, and visualization of Group Concept Mapping studies. 2023. Accessed May 15, 2022. https://groupwisdom.com
12. Dos Santos Marques IC, Theiss LM, Johnson CY, McLin E, Ruf BA, Vickers SM, et al. Implementation of virtual focus groups for qualitative data collection in a global pandemic. *Am J Surg*. 2021;221(5):918–922. doi:10.1016/j.amjsurg.2020.10.009
13. Keen S, Lomeli-Rodriguez M, Joffe H. From challenge to opportunity: virtual qualitative research during COVID-19 and beyond. *Int J Qual Methods*. 2022;21:16094069221105075. doi:10.1177/16094069221105075
14. Dey BL, Al-Karaghouli W, Muhammad SS. Adoption, adaptation, use and impact of information systems during pandemic time and beyond: research and managerial implications. *Inf Syst Manage*. 2020;37(4):298–302. doi:10.1080/10580530.2020.1820632
15. National Cancer Institute. NCI-designated cancer centers. Updated May 31, 2024 . Accessed July 15, 2022. https://www.cancer.gov/research/infrastructure/cancer-centers
16. Paskett ED, Hiatt RA. Catchment areas and community outreach and engagement: the new mandate for NCI-designated cancer centers. *Cancer Epidemiol Biomarkers Prev*. 2018;27(5):517–519. doi:10.1158/1055-9965.EPI-17-1050
17. National Cancer Institute. Quick profiles: Kentucky. 2022. Accessed June 1, 2024. https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statename=kentucky
18. Centers for Disease Control and Prevention. 2019 BRFSS Survey Data and Documentation. Last reviewed August 28, 2024. Accessed April 15, 2022. https://www.cdc.gov/brfss/annual_data/annual_2019.html
19. National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Program. Accessed April 15, 2022. http://www.seer.cancer.gov
20. US Census Bureau. About the American Community Survey. Page last revised June 18, 2024 . Accessed January 2022. https://www.census.gov/programs-surveys/acs/about.html
21. ResearchMatch. What is ResearchMatch? 2024. Accessed June 1, 2024. https://www.researchmatch.org
22. Reyes C, Thompson B, Briant KJ, Mendoza J. Understanding a diverse cancer center catchment area: a qualitative needs assessment built on a theoretical framework. *Cancer Contr*. 2020;27(1):1073274820983026. doi:10.1177/1073274820983026
23. Otto AK, Ketcher D, McCormick R, Davis JL, McIntyre MR, Liao Y, et al. Using the health belief model to assess racial/ethnic disparities in cancer-related behaviors in an NCI-designated comprehensive cancer center catchment area. *Cancer Causes Control*. 2021;32(10):1085–1094. doi:10.1007/s10552-021-01457-7
24. McCloud RF, Bekalu MA, Maddox N, Minsky SJ, Viswanath K. Leveraging breadth and depth: strategies to characterize population diversity to address cancer disparities in the DF/HCC catchment area. *Cancer Epidemiol Biomarkers Prev*. 2019;28(3):435–441. doi:10.1158/1055-9965.EPI-18-0799
25. Paskett ED, Young GS, Bernardo BM, Washington C, DeGraffinreid CR, Fisher JL, et al. The CITIES Project: understanding the health of underrepresented populations in Ohio. *Cancer Epidemiol Biomarkers Prev*. 2019;28(3):442–454. doi:10.1158/1055-9965.EPI-18-0793
26. Ravaghi H, Guisset AL, Elfeky S, Nasir N, Khani S, Ahmadnezhad E, et al. A scoping review of community health needs and assets assessment: concepts, rationale, tools and uses. *BMC Health Serv Res*. 2023;23(1):44. doi:10.1186/s12913-022-08983-3

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

27. US Census Bureau. Kentucky: 2020census. August 25, 2021. Accessed August 15, 2024. https://www.census.gov/library/stories/state-by-state/kentucky-population-change-between-census-decade.html
28. Burus T, Thompson JR, McAfee CR, Williams LB, Knight JR, Huang B, et al. A framework and process for community-engaged, mixed-methods cancer needs assessments. *Cancer Causes Control*. 2024. doi:10.1007/s10552-024-01892-2

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Tables

Table 1. Demographic Characteristics of Participants Who Completed Sorting and Rating Activities in the Concept Mapping Process Conducted as Part of a Statewide Assessment of Community Cancer Needs, Kentucky, 2021[a]

Characteristic	Community members (n = 51)	Organizational partners (n = 42)	All (N = 93)
Age, mean (SD), y	49.9 (13.5)	50.1 (13.6)	50.0 (13.5)
Race and ethnicity[b]			
American Indian or Alaska Native	2 (3.9)	1 (2.4)	3 (3.2)
Asian or Asian American	3 (5.9)	0	3 (3.2)
Black or African American	11 (21.6)	4 (9.5)	15 (16.1)
Hispanic, Latin American, or Spanish origin	1 (2.0)	0	1 (1.1)
White	39 (76.5)	38 (90.5)	77 (82.8)
Education			
Completed high school or GED	4 (7.8)	2 (4.8)	6 (6.4)
Some college or vocational school	10 (19.6)	4 (9.5)	14 (15.0)
Bachelor’s degree or higher	37 (72.6)	36 (85.7)	73 (78.5)
Health insurance[b]			
Employer, military, or private	29 (56.9)	37 (88.1)	66 (71.0)
Medicaid	10 (19.6)	1 (2.4)	11 (11.8)
Medicare	14 (27.4)	3 (7.1)	17 (18.3)
Kentucky health insurance marketplace	1 (2.0)	1 (2.4)	2 (2.2)
Gender identity			
Woman	39 (76.5)	35 (83.3)	74 (79.6)
Man	11 (21.6)	5 (11.9)	16 (17.2)
Non-binary or Genderqueer	1 (2.0)	2 (4.8)	3 (3.2)
Identified as LGBTQ+			
Yes	5 (9.8)	2 (4.8)	7 (7.5)
No	46 (90.2)	39 (92.9)	85 (91.4)
Prefer not to answer	0	1 (2.4)	1 (1.1)
Family (including participant) history of cancer			
Yes	45 (88.2)	39 (92.9)	84 (90.3)
No or not to my knowledge	6 (11.8)	3 (7.1)	9 (9.7)

Abbreviations: GED, General Educational Development; LGBTQ+, lesbian, gay, bisexual, transgender, queer.

[a] All values are number (percentage) unless otherwise indicated. Percentages may not add to 100 because of rounding.

[b] Responses not mutually exclusive.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

Table 2. Additional Identified Focus Areas and Strategies by Participant Type and Region in Kentucky[a]

	Participant type		Region	
Area or strategy	**Community members**	**Organizational partners**	**Western Kentucky**	**Eastern Kentucky**
Focus area	59. Breast cancer screening rates are similar to rates in the US but still need improvement 61. Lower rates of cervical cancer screening in rural areas and Appalachia 67. Some cancers linked to environment exposures are more common than in the US overall (examples: lung, kidney, melanoma, leukemia, bladder)	63. Cancers related to tobacco are higher than in the US overall (some of the worst rates of lung, head/neck, kidney, and bladder cancers) 74. 1 in 3 adults fail to get any physical activity outside of work (third worst in the US)	64. Cancers related to obesity are higher than in the US overall (some of the worst rates for colorectal, pancreatic, and brain cancers) 73. 1 in 5 youth and 2 in 5 adults are obese (among the highest rates in the US)	60. Lower colorectal cancer screening rates in Appalachia 74. 1 in 3 adults fail to get any physical activity outside of work (third worst in the US)
Strategy	**Cluster 2: Education, integrative support, and outreach**			
	24. Financial support for cancer treatment (examples: grants, foundation assistance, financial advisor)	55. Partnering with community organizations to share health information (examples: schools, faith-based, employers, local leaders)	55. Partnering with community organizations to share health information (examples: schools, faith-based, employers, local leaders) 58. Use of multiple media sources for health information (examples: mail, flyers, advertisements, websites, social media)	2. Health promotion programs by local organizations (examples: HPV vaccination, nutrition, tobacco cessation)
	Cluster 3: Equitable accessibility			
	27. Access to hospice or comfort care	11. Quality or trust of local health care facilities 41. Health information at low reading levels	22. Access to affordable nicotine replacement products (examples: patches, gum, lozenges) 27. Access to hospice or comfort care	3. Access to places with affordable healthy foods (examples: grocery stores, farmers markets) 38. Bilingual staff or interpreters 41. Health information at low reading levels

[a] Numbers refer to identification numbers for items identified in concept mapping (Appendix).

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Appendix . List of Final Concept Mapping Items Sorted by Cluster

Cluster	Item identification no.	Item
1. Proactive behaviors for improved health	1	Access to places to be active or exercise (examples: parks, sidewalks, gyms, recreation centers)
	4	Smoke-free policies for secondhand smoke exposure
	29	Side effects related to cancer treatment (examples: “chemo brain,” nutritional needs, gender/sexual health, pain)
	35	Health habits formed as children
	42	Building skills for healthy behaviors (examples: physical activity, sleep, healthy eating)
	44	Stress management and healthy coping skills
	56	Employer supports for healthy lifestyle choices
	57	Testimonials of personal cancer experiences
2. Education, integrative support, and outreach	2	Health promotion programs by local organizations (examples: HPV vaccination, nutrition, tobacco cessation)
	23	Advocates or navigators to guide patients through cancer treatment
	24	Financial support for cancer treatment (examples: grants, foundation assistance, financial advisor)
	25	Mental health, spiritual support, and other assistance programs for cancer patients/caregivers
	28	Doctors explaining how different treatments may affect quality of life
	40	Culturally appropriate health information
	43	Building skills to speak up and ask questions at health care visits
	49	Information about risk of getting cancer again in the future (if in remission)
	50	Talking with relatives and doctors about family health history
	51	Information on ways to reduce risks of getting cancer
	52	Information on who should get cancer screening and when
	54	Information on how to use insurance benefits (examples: free preventive care, copays, allowed health care providers)
	55	Partnering with community organizations to share health information (examples: schools, faith-based, employers, local leaders)
	58	Use of multiple media sources for health information (examples: mail, flyers, advertisements, websites, social media)
3. Equitable accessibility	3	Access to places with affordable healthy foods (examples: grocery stores, farmers markets)
	5	Access and availability of high-speed internet
	6	Distance to hospitals or clinics
	11	Quality or trust of local health care facilities
	13	Access to at-home cancer screening (examples: Cologuard, fecal sample tests)
	14	Access to genetic screening and testing
	15	Access to needed doctors and specialists
	16	Availability of community health workers
	17	Bringing cancer screening to local communities (examples: mobile units, more screening locations)
	18	Out-of-pocket health care costs (examples: medications, treatment procedures)
	19	Expanded access to Medicaid
	20	Insurance coverage of pre-existing conditions

Abbreviations: HPV, human papillomavirus; LGBTQ+, lesbian, gay, bisexual, transgender, queer.

(continued on next page)

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

(continued)

Cluster	Item identification no.	Item
	21	Telehealth options for health care services
	22	Access to affordable nicotine replacement products (examples: patches, gum, lozenges)
	26	Help for traveling to cancer treatment (examples: car, gas, place to stay, someone to drive you)
	27	Access to hospice or comfort care
	30	Clear communication between health care providers and patients
	31	Communication across multiple doctors about a patient's care
	32	Getting second or third opinions of treatment options
	33	Established relationship and trust with a health care provider
	34	General trust or confidence in health care
	37	Access to diverse/minority health care providers
	38	Bilingual staff or interpreters
	41	Health information at low reading levels
4. Perceptions, beliefs, and stigmas	7	Pollution in water, air, or soil that can cause cancer
	8	Stigma surrounding cancer
	10	Other priority health issues in the community besides cancer (example: addiction, diabetes)
	12	Stigma around mental health
	36	Vaping (examples: Juul, e-cigarettes)
	39	Cultural beliefs about seeking health care (examples: rural/Appalachian, immigrants, African American, LGBTQ+)
	45	Embarrassment or privacy concerns about cancer diagnosis
	46	Belief that changing behavior won't make a difference (examples: smoking, nutrition, exercise)
	48	Fear or avoiding cancer screenings (examples: out-of-sight/out-of-mind mentality)
	53	Myths around cancer treatments and chances of surviving cancer
5. "Kentucky Uglies": Current status of cancer and risk factors	9	Community ties to local industry (examples: tobacco, mining, farming, factories)
	63	Cancer rates related to tobacco are higher than in the US overall (some of the worst rates of lung, head/neck, kidney, and bladder cancers)
	64	Cancers rates related to obesity are higher than in the US overall (some of the worst rates of colorectal, pancreatic, and brain cancers)
	65	Cancers rates related to HPV are higher than in the US overall (some of the worst rates of cervical and head/neck cancers)
	66	New hepatitis C virus infection rate is among the highest in the US (linked with opioid injection use/a known cause of liver cancer)
	67	Some cancers linked to environmental exposures are more common than in the US overall (examples: lung, kidney, melanoma, leukemia, bladder)
	70	Higher cancer death rates in counties with lower education versus higher education
	72	About 1 in 4 adults are current smokers, with higher rates in Appalachia (second-highest rate in the US)
	73	1 in 5 youth and 2 in 5 adults are obese (among the highest rates in the US)
	74	1 in 3 adults fail to get any physical activity outside of work (third-worst in the US)
6. Disadvantages in Appalachian, Black, and Hispanic communities	47	Hassle/unpleasantness of cancer screening
	59	Breast cancer screening rates are similar to rate in US overall but still need improvement

Abbreviations: HPV, human papillomavirus; LGBTQ+, lesbian, gay, bisexual, transgender, queer.

(continued on next page)

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

(continued)

Cluster	Item identification no.	Item
	60	Lower colorectal cancer screening rates in Appalachia
	61	Lower cervical cancer screening rates in rural areas and Appalachia
	62	Lung cancer screening rates are low (even worse in the Black community)
	68	More people die from certain cancers in rural and Appalachian areas than the US overall (examples: lung, colorectal, kidney, leukemia)
	69	More Black Kentuckians die from certain cancers than White Kentuckians (examples: uterine, prostate, stomach, myeloma)
	71	Only about half of youth are fully vaccinated against HPV (even less in rural areas)
	75	Higher levels of poverty among rural, Appalachian, Black, and Hispanic Kentuckians than among the US population
	76	One-third of counties have more than 20% of people living in persistent poverty since 1980 (mostly in rural Appalachia)
	77	Fewer adults have a college degree than in the US overall (even lower among rural, Appalachian, Black, and Hispanic Kentuckians)
	78	Math and reading proficiency scores among K-12 public school students are often lower than the US average
	79	Workers are more likely than workers in the US overall to hold jobs at or below minimum wage, especially women
	80	1 in 4 Hispanic Kentuckians have no health insurance (otherwise Kentucky's uninsured rates are better than US rates)

Abbreviations: HPV, human papillomavirus; LGBTQ+, lesbian, gay, bisexual, transgender, queer.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 22, E23 JUNE 2025

TOOLS FOR PUBLIC HEALTH PRACTICE

Engaging a Community-Academic Partnership to Implement Community-Driven Solutions

Abiola O. Keller, PhD, MPH, PA-C[1]; Lindsey St. Arnold Bell, MS[2]; Kristin Haglund, PhD, RN[1]

Accessible Version: www.cdc.gov/pcd/issues/2025/24_0334.htm

Suggested citation for this article: Keller AO, St. Arnold Bell L, Haglund K. Engaging a Community-Academic Partnership to Implement Community-Driven Solutions. Prev Chronic Dis 2025; 22:240334. DOI: https://doi.org/10.5888/pcd22.240334.

PEER REVIEWED

Summary

What is already known on this topic?

Community-engaged research offers a mutually beneficial approach for communities and organizations/institutions to work together to solve entrenched issues that contribute to inequities, decrease public health, and impede quality of life. Little is known about leveraging community–academic partnerships to implement change.

What is added by this report?

We provide an example of a community–academic project that harnessed the knowledge and expertise of residents to inform interventions to support better acceptance, uptake, and efficacy.

What are the implications for public health practice?

Our work highlights the significance of projects incorporating community engagement principles within the context of a community–academic partnership to generate solutions aligned with partners' priorities.

Abstract

Community engagement is a pivotal public health tool for addressing population health challenges and advancing health equity. Community–academic partnerships that use community-engaged approaches can prioritize community strengths and ensure that resources and interventions match local needs. In 2021–2022, a community-academic partnership, guided by the principles of community engagement, collaborated with residents of Milwaukee's Near West Side (NWS) to identify strengths and assets and prioritize actions to improve health and quality of life. To inform the development of a planned community resource center, residents were invited for group concept mapping (GCM). GCM includes idea generation, sorting and rating, and developing cluster maps. Residents (N = 165) generated 71 unique ideas in response to the question, "To make the Near West Side a healthier community we need _____." Residents sorted ideas into clusters based on conceptual similarity and prioritized the importance of each. Data were managed with The Concept System Global MAX Software. By using the 71 ideas, a cluster map with 9 domains best fit the data. Domains were high-quality and affordable housing, community-engaged public safety, health and wellness services, strong and inclusive neighborhoods, investments in young people, public infrastructure, sustainable businesses, alternative modes of transportation, and vibrant social spaces. Eight of the 9 domains were highly rated for importance. These domains became focus areas for our partnership's efforts to advance health and well-being in NWS. Our work highlights the significance of projects incorporating community engagement principles within the context of a community–academic partnership to generate mutually beneficial solutions that are strength-based and aligned with partners' priorities.

Community Engagement to Advance Public Health Equity

In urban centers, equity issues related to public health and quality of life are complex. Economic disadvantage is often concentrated and can adversely affect the health of residents, prevent investment and development, deter patronage of local businesses, and contribute to actual or perceived increased crime rates. Community-engaged research (CEnR) is a mutually beneficial approach for communities, organizations, and institutions to work together to create solutions that promote equity and public health and improve quality of life.

CEnR is an umbrella term for participatory-oriented research methodologies (1). In CEnR, peoples' lived experiences are important sources of knowledge. Benefits of using CEnR methodologies in public health improvement projects include identification of more nuanced and specific etiologies of underlying problems, identification of strengths and assets of populations, creation of in-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

terventions with increased likelihood of success, and generation of results that are relevant, timely, and useful to populations.

Different methodologies can be used to conduct CEnR, but 9 principles put forth by the Clinical and Translational Science Awards Consortium Community Engagement Key Function Task Force summarize the fundamental principles of this approach (2):

1. Transparency of purpose, goals, and participation
2. Shared knowledge of history and contexts of the community
3. Relationships that cultivate trust and reciprocity
4. Respect for the self-determination of a community and of its individual members
5. Inclusive partnerships
6. Diverse and culturally centered
7. Strength and asset-based
8. Co-created with shared governance
9. Sustainable

Community–academic partnerships (ie, equitable partnerships between local communities and academic research institutions) are a key tool for successfully conducting CEnR. Community–academic partnerships can provide opportunities for collaborators to augment their impact by focusing resources and increasing capacity (3). Although literature describing examples of, and factors related to, establishing and sustaining community–academic partnerships exist (4–8), literature documenting how to leverage such partnerships to implement community-driven solutions is sparse. In this article, we present an example of a community–academic partnership working to improve health and quality of life in a community. Our partnership enacted principles of community engagement (2) to engage community members in assessing strengths and assets, prioritizing actions for meaningful change, and elucidating perspectives on how to advance the health of the community.

The Community and Partners

Milwaukee's Near West Side (NWS), a "neighborhood of neighborhoods," comprises 7 unique neighborhoods and is home to approximately 29,000 residents. This area was once known for thriving commercial corridors, strong connections among residents, and major employers. However, in a 20-year period, beginning in the 1970s, many large organizations, including hospitals, a medical college, and a university, left NWS, with an accompanying loss of family-sustaining jobs. With these changes, NWS lost its identity as a thriving commercial and residential corridor and instead became the hub of a city known for being among the nation's most impoverished, incarcerated, and racially segregated (9). The median household income in NWS is $18,686, which means that 42% of its children and 46% of its families live in poverty compared with 24% of families overall who live in poverty in Milwaukee (10). The unemployment rate in NWS neighborhoods ranges from 7.3% to 14.4%, compared with 6.8% for Milwaukee overall (10).

To revitalize NWS and sustain thriving business and residential corridors, Near West Side Partners (NWSP) was founded in 2014 through the support of 5 institutions: Aurora Health Care (now Advocate Aurora Health), Harley-Davidson, Marquette University, MillerCoors (now MolsonCoors Beverage Company), and Potawatomi Business Development Corporation (now Potawatomi Ventures). As a nonprofit organization, NWSP's goal is to make NWS a great place to live, work, play, and stay. In 2021, NWSP embarked on an initiative to establish a community resource center in NWS. It was imperative that residents of NWS be included in planning the space, amenities, and services for the resource center. As such, NWSP partnered with researchers in Marquette University's College of Nursing to design and implement a project that would use the principles of community engagement to identify and prioritize community-driven solutions for a healthier community.

Respect for the self-determination of a community and of its individual members is critical for the sustained success of any improvement initiative (2). Self-determination is supported when community members are included in planning and implementing strategies and evaluating outcomes. As such, Group Concept Mapping (GCM) was selected as an ideal methodologic approach for this work because it provides a structured, collaborative process for generating a model of how members of the community conceptualize a healthy community (11). GCM is a way to promote the self-determination of a community and to systematically gather ideas from many people and organize those ideas into actionable priorities. Previous studies have used GCM to create frameworks (12), prioritize strategies (13), inform health-related research (14–16), and plan and evaluate programs (17).

The Group Concept Mapping Process

The GCM process consisted of 5 steps: 1) preparation, 2) idea generation, 3) sorting and rating, 4) creating maps, and 5) interpreting maps (Figure 1) (18). One author (A.O.K.) trained as a concept-mapping facilitator and oversaw each session. In 2021, data were collected from June through November. There were 165 participants for idea generation and 138 for sorting and rating. Of the sorting and rating participants, 59% were female, 77% African American, 54% aged younger than 45 years, and 93% renting their current home. Participants represented all 7 neighborhoods. All participants in idea generation and about two-thirds of participants in sorting and rating were residents of NWS. The project

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

was reviewed by Marquette University's institutional review board, which determined the study was not human subjects research because the intent was not to create generalizable knowledge. The study was conducted in English only.

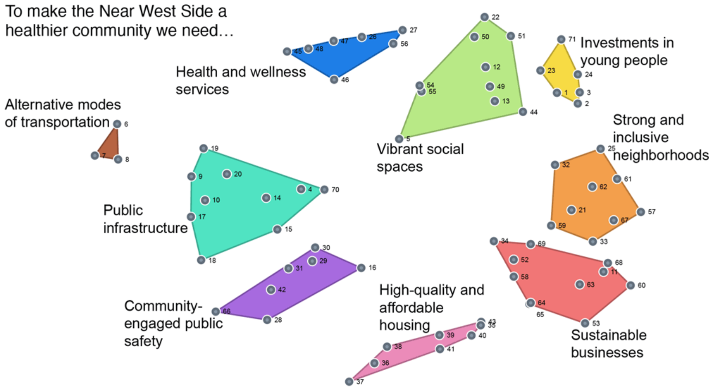


Figure 1. Group concept mapping cluster map showing solutions within 9 domains. The map displays ideas for improving community health and quality of life contained in each domain. The smaller in size the cluster, the greater the interrelationship between ideas within the cluster.

GCM step 1

Preparation. The intent of our GCM project was to gather actionable ideas from community members. A focus prompt is the question stem that participants respond to when brainstorming ideas. For our project, we aimed to devise a focus prompt that would elicit strength-based responses. We pilot tested 2 focus prompts: A, "To make the Near West Side a healthier community we need _____?" and B, "To make the Near West Side a great place to live, work, play, and stay we need _____?" Both prompts were pilot tested with a group of 6 NWSP staff members who were also NWS residents. Prompt A generated a greater volume of responses that reflected actionable items than prompt B. Therefore, we used only focus prompt A in the subsequent steps of our project.

GCM step 2

For the second step, idea generation, we invited adult community members to share their ideas for making NWS a healthier community. The goal of idea generation was to elicit a wide range of actionable ideas in response to focus prompt A, "To make the Near West Side a healthier community we need ____?" To maximize participation of community residents in idea generation, we added the focus prompt to the 2021 annual NWS resident survey. The resident survey is an electronic survey conducted door-to-door by the NWSP staff. The survey was also administered at community gatherings. Residents either responded orally and the NWSP representative entered their responses, or residents used the representative's hand-held device to complete the survey themselves. Some residents accessed and completed the survey on their own devices through a link provided by an NWSP representative.

Focus prompt A generated 317 responses. First, we reviewed the responses and eliminated duplicate ideas. The remaining responses were synthesized into a list of ideas by editing for clarity, dividing responses that contained more than one idea into unique ideas, and grouping similar ideas into one idea. A list of 71 unique ideas was shared with NWSP's executive director and associate director for review to ensure that all original ideas from the community were represented. The NWSP staff agreed that the 71 items were reflective of the ideas brought forth in the idea generation step. The final list included 71 discrete actionable ideas that were then used in the remaining GCM steps.

GCM step 3

Sorting and rating. To recruit residents to participate in sorting and rating, flyers were distributed as door hangers and posted at neighborhood businesses, a public housing facility, and on the NWSP Facebook page. Sorting and rating took place in person at 2 readily accessible community sites. One session was held at a public housing facility dedicated to adults who are older and disabled, and multiple sessions were held over 2 weeks at a locally owned restaurant. Customers who came into the restaurant were also invited to participate. Volunteers, including Marquette University faculty, staff, and students and NWSP staff, sat with residents while they completed sorting and rating to provide instructions, to be available for questions, and to read ideas aloud for those who preferred that. As a token of appreciation, a $15 gift card, the cost of a complete meal at the restaurant, was provided to each person who completed the sorting and rating activity.

The sorting and rating activity was performed manually by each participant. For sorting, participants received a set of 71 cards. Each card was printed with 1 idea from the final list of ideas. Participants sorted the ideas into groups based on their interpretation of how the ideas were related. Participants were instructed to create more than 1 group and to place each card in only 1 group. After sorting all ideas into groups, participants provided names for their groups. Each person's stacks of grouped cards with group name on the top card were paper-clipped together. Later, the name and ideas (identified by number) in each group were manually entered into The Concept System Global MAX software (Concept Systems Incorporated), a web-based platform for data management and analysis.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Rating of ideas followed sorting. Participants rated each idea based on 2 importance variables: 1) how important it was for making NWS a healthier community and 2) how important it was for making NWS a great place to live, work, play, and stay. Ratings were recorded on a 5-point Likert scale, ranging from 1, relatively unimportant, to 5, extremely important. The rating sheets were collected, and data were manually entered into The Concept System Global MAX software (Concept Systems Incorporated).

GCM step 4

Creating maps. We used The Concept System Global MAX software to perform multidimensional scaling and hierarchical cluster analyses to generate cluster maps. A cluster map is a visual representation of how ideas are grouped or clustered together by participants. First, we created a point map by using a 2-dimensional multidimensional scaling analysis. On the point map, each point represented 1 idea, with distances between points determined by the frequency with which participants sorted the represented ideas into the same group. Ideas sorted together more frequently by more people resulted in smaller clusters. Next, using hierarchical cluster analysis, we partitioned the point maps into nonoverlapping clusters reflecting unique domains. This analytic approach produced many possible cluster solutions (ie, multiple maps with a varying number of clusters) from 1 point map. In the GCM methodology there is no predetermined appropriate number of clusters (18). Researchers, participants, and other invested parties collaboratively determined the ideal cluster solution (ie, number of clusters that resulted in conceptually meaningful and distinct domains).

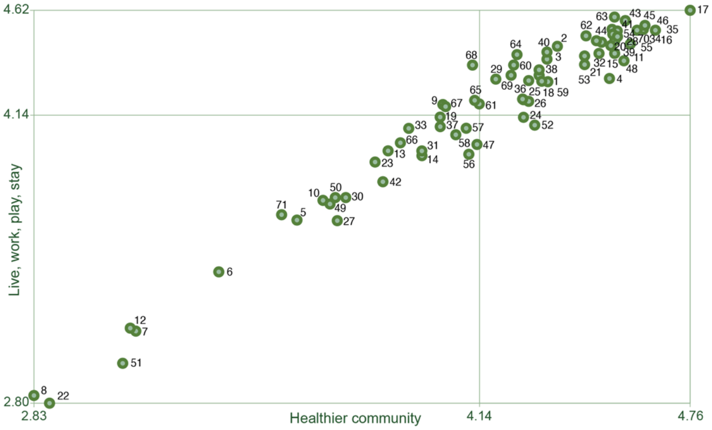
Finally, by using the rating data, we generated a go-zone map to illustrate the prioritization of each idea based on the 2 importance variables — importance for a healthy community and importance for making NWS a great place to live, work, play, and stay. A go-zone chart is a bivariate plot with a point for each idea based on the average rating for the 2 importance variables. The go-zone chart comprises 4 quadrants made by dividing above or below the mean on the x-axis (healthy community) and the y-axis (live, work, play, and stay). Ideas in the upper-right quadrant represents those perceived to be important for a healthy community and for making NWS a great place to live, work, play, and stay.

GCM step 5

Interpreting maps. During a final session, we invited NWS residents and staff from NWSP to meet as a group to review and provide feedback on the maps and their interpretations. First, we reviewed the point maps. We then reviewed the cluster maps we created. We presented attendees with the maps for clusters solutions ranging from 5 to 15 clusters (ie, in a 5-cluster solution, all 71 ideas were contained within 5 cluster groupings). The cluster map with 9 cluster groupings or domains was selected as the one that best represented participants' priorities (Figure 1). We asked residents and staff members to read the ideas within each domain and to name that domain by suggesting a short phrase that best described the set of ideas. These suggested names guided the final domain names, which are high-quality and affordable housing, community-engaged public safety, health and wellness services, strong and inclusive neighborhoods, investments in young people, public infrastructure, sustainable businesses, alternative modes of transportation, and vibrant social spaces. We included individual ideas within each domain (Table).

Finally, we created a go-zone that consisted of ideas prioritized as important for a healthy community and important for making NWS a great place to live, work, play, and stay (Figure 2). Across domains, 38 ideas were identified as being of high importance for both goals. These ideas represented 8 of the 9 domains. The domain "Alternative modes of transportation" was not represented in the go-zone.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.



Items represented in Go-Zone (ie, above average importance on both axes)

01	Youth centers
02	Childcare
03	Children's recreation programs
04	Address lead in the water
11	Opportunities for people of color (black) to build businesses
15	Lights at night
16	Smoke detectors for homes
17	To control reckless driving
18	Street cameras and doorbell cameras
20	Street repair
21	Information about services provided in the community
25	Programs where older adults and young people can meet and work together
26	Safe spaces to work out
28	Police that understand the perspectives of residents
29	Police to be more involved with the youth
32	People that can help the elderly
34	More people employed
35	Higher wages
36	Childcare
38	Take down poorly run apartments
39	Housing stability for renters
40	Resources for homes that need repairs
41	Affordable and high quality housing
43	Less homelessness
44	A place for community health and wellness programs
45	Access to mental health care
46	A health clinic
48	Hospitals
53	Community investments by the city
54	Access to nutritious foods
55	A grocery store
59	A stronger sense of community
60	Communication among residents
62	Support of neighborhood schools
63	Funding to improve the area
64	Investment in businesses
69	Communication with neighbors
70	Trash cans and frequent trash collection

Figure 2. Go zone for Milwaukee's Near West Side with points depicting average rating of importance for each idea. Four quadrants represent categories of community priorities based on 2 dimensions: "live, work, play, stay" (vertical axis) and "healthier community" (horizontal axis). Each quadrant represents a specific combination of high or low scores on these dimensions. On the vertical axis, the higher scores indicate greater importance within that dimension. On the horizontal axis, higher scores indicate greater importance. Ratings for importance for live, work, play stay (y-axis) range from 2.80 to 4.62 (mean 4.14) on scale of 1 to 5. Ratings for importance for healthier community (x-axis) range from 2.83 to 4.76 (mean 4.14) on scale of 1 to 5. Pearson's product moment correlation coefficient *r* = 0.98.

Enacting Principles of Community Engagement

NWSP has been physically embedded in the NWS of Milwaukee for 10 years. The organization and community residents have established routine communication pathways, hold regular shared events, and engage in joint community improvement efforts. Through intentional engagement, a shared knowledge of the history and contexts of the community serves as a foundational community engagement principle necessary to build a relationship of mutuality and trust (2). Having this baseline relationship provided a firm foundation for implementing a project designed to work with community residents to realize meaningful, sustainable change and improvements.

The project team included Marquette University researchers, staff, and students; NWSP leaders; and NWSP ambassadors. NWSP ambassadors were a unique asset because they both lived in NWS and worked for NWSP. The project team used a collaborative approach to make several key decisions in the research process (eg, focus prompt selection, incentives for participants, location of activities, domain names). This approach to decision-making helped to strengthen relationships within the project team. As part of the project team, NWSP ambassadors took the lead in presenting the project to residents, orienting volunteers to help with data collection, assisting participants with completing the sorting and rating, and serving as contact persons for questions and concerns. Because of the ambassadors' dual role as NWSP staff and NWS residents, this model of shared leadership fostered trust and reciprocity within the project team and between the project team and community residents.

Another key principle of community engagement is co-creation with shared governance and sustainability (2). A critical element of this project was the feedback loop to share our results with the residents and the academic community. An important aspect of sustainability was delivering results that showed that peoples' recommendations were included. In this project, the domains identified through the GCM process (Figure 2) were recognized as the community's vision and priorities. NWSP used these priorities to determine the organizations that would be ideal occupants to engage in conversations about the opportunity to be a tenant or service provider in the resource center. The resource center (now named Concordia 27) aligns with the domain of vibrant social spaces. It houses a café and ample space for residents and other community members to connect, collaborate, and build community. In addition to NWSP, Concordia 27 is home to a community-based organization specializing in wellness and trauma-informed education, trainings, and services (health and wellness services domain) and another community-based organiz-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

ation that provides workforce training for people with intellectual disabilities and those who were previously incarcerated (sustainable business domain). Concordia 27 also provides a kitchen incubator space and floor space for emerging small businesses. The domain of high-quality and affordable housing is addressed through the inclusion of 33 housing units that will be available for rent by senior citizens and working families.

Conclusion

Community engagement in research operates on a continuum (19). We have described how a community–academic partnership, guided by the principles of community engagement, incorporated the perspectives of a diverse group of community members into a shared view of a healthy community. The project demonstrated 2 types of participatory relationships described previously by Key et al (19). First, the relationship between NWSP and researchers from Marquette University College of Nursing exemplifies a community-driven, community-led relationship given that NWSP identified a need and led the project with support from the college. Second, during the GCM process, community residents contributed equally to decision-making related to idea generation, the number and names of the domains, and the prioritization of the community-generated items.

Our findings underscore the importance of the social determinants of health for achieving overall health and well-being (20). By using a collaborative process, we identified several focus areas for community health interventions and programs. This work adds to a growing body of literature demonstrating how community–academic partnerships can harness available resources to effect change and advance shared goals (8,21,22).

Our project was overtly strength- and asset-based. Participants were acknowledged as experts on their lives and the neighborhoods in which they lived. Valuing people’s strengths and recognizing that community members are assets conveys respect. The focus prompt used to brainstorm ideas was strength-based; we did not ask for a list of deficits, nor did we use language that identified NWS or the people who live there as deficient. The GCM process invited community members to identify and prioritize actionable ideas. People increase involvement in initiatives when they identify with issues that they consider important, feel that they have influence in the initiative, and can make meaningful contributions toward the solution. Moreover, we minimized barriers to participation in the GCM process by advertising in advance through flyers delivered to homes and postings in visible locations. The data collection locations were readily accessible. To recognize the value of participants’ contributions we provided a gift certificate for a meal at a locally owned restaurant (one of the data collection sites).

Although community–academic partnerships are an opportunity to share, pool, and increase assets, the financial resources needed for Concordia 27 were beyond the capacity of the partnership. While NWSP founding institutions played a vital role in advocating for public funding for the project, their financial contributions were limited to furnishing and equipping the building. The findings from the GCM process provided critical insights into local needs and priorities, helping to shape Concordia 27 and attract investors who aligned with the community-engaged approach. The intentional collaboration with the community bolstered Concordia 27’s case for support and facilitated securing the necessary funding. The Concordia 27 project was launched with significant investment ($2 million or greater) from the State of Wisconsin, the federal government, and Milwaukee County. Additional funding was secured through historic tax credits, owner equity, and lending.

Although this project was conducted in the context of a longstanding, institutionalized collaboration, implementing the principles of community engagement though structured and participatory methodologies such as GCM can support building or growing a community–academic partnership. The amount of time that a partnership has been in existence is an important consideration when co-creating action plans and priorities. To facilitate success, outcomes and deliverables should be scaled to appropriately reflect the characteristics of the partnership and the resources available.

Engaging with community is a process that requires preparation, training, and intentionality. Community engagement and CEnR can generate mutually beneficial solutions that are strength-based, relevant, and aligned with partners’ priorities (3). Collaborating with communities harnesses the knowledge and expertise that individuals have about their own lives, informing interventions for better acceptance, uptake, and efficacy (23). For those seeking to address public health challenges and health equity, community engagement and CEnR are critical elements in the public health toolkit.

Acknowledgments

The authors thank all the community members and members of the Marquette University College of Nursing community who participated and supported the project. The authors declare no potential conflicts of interest with respect to the research, authorship, or publication of this article. The authors received no external financial support for the research, authorship, or publication of this article. No copyrighted material, surveys, instruments, or tools were used in the research described in this article.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

Author Information

Corresponding author, Abiola O. Keller PhD, MPH, PA-C, Marquette University College of Nursing, PO Box 1881, Milwaukee WI 53201-1881 (abiola.keller@marquette.edu).

Author Affiliations: [1]College of Nursing, Marquette University, Milwaukee, Wisconsin. [2]Near West Side Partners, Milwaukee, Wisconsin.

References

1. Ortiz K, Nash J, Shea L, Oetzel J, Garoutte J, Sanchez-Youngman S, et al. Partnerships, processes, and outcomes: a health equity-focused scoping meta-review of community-engaged scholarship. *Annu Rev Public Health.* 2020;41(1):177–199. doi:10.1146/annurev-publhealth-040119-094220
2. Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee. Task Force on the Principles of Community Engagement. *Principles of Community Engagement.* 2011. Accessed December 10, 2024. https://stacks.cdc.gov/view/cdc/11699/cdc_11699_DS1.pdf
3. Noel L, Phillips F, Tossas-Milligan K, Spear K, Vanderford NL, Winn RA, et al. Community–academic partnerships: approaches to engagement. *Am Soc Clin Oncol Educ Book.* 2019;39(39):88–95. doi:10.1200/EDBK_246229
4. Bustos T, Simkani S, Sridhar A, Drahota A. "Good solid relationships make programs work": a mixed methods assessment of determinants to community research partnerships in Flint, MI. *Collaborations: A Journal of Community-Based Research and Practice.* 2024;7(1):1. doi:10.33596/coll.123
5. Haglund K, Ortiz A, De Los Santos J, Garnier-Villarreal M, Belknap RA. An engaged community–academic partnership to promote positive youth development. *J Community Engagem Scholarsh.* 2021;13(2). doi:10.54656/LNWP6978
6. Clark R, Gaber J, Datta J, Talat S, Bomze S, Marentette-Brown S, et al. Understanding collaborative implementation between community and academic partners in a complex intervention: a qualitative descriptive study. *BMC Health Serv Res.* 2023;23(1):606. doi:10.1186/s12913-023-09617-y
7. Drahota A, Meza RD, Brikho B, Naaf M, Estabillo JA, Gomez ED, et al. Community-Academic partnerships: a systematic review of the state of the literature and recommendations for future research. *Milbank Q.* 2016;94(1):163–214. doi:10.1111/1468-0009.12184
8. Velez G, Haglund K, Durkin T, Cashman M, Walker S. A university and school partnership: building tools for reconciliation, healing, and resilience. *Best Practices in Jesuit Higher Education.* 2023;3:69–75.
9. Schmid J. Heavy job losses since the 1970s hit Milwaukee's black community the hardest. Here's why. *Milwaukee Journal Sentinel.* August 27, 2019. Accessed December 10, 2024. https://www.jsonline.com/story/news/solutions/2019/08/27/milwaukees-job-losses-since-1970-hit-black-community-hardest/2051985001/
10. US Census Bureau. American Community Survey 5-Year Estimates, 2018. Accessed April 10, 2020. http://www.census.gov/data/developers/data-sets/acs-5year.2018.html
11. Walker RE, Jones JR, Burke JG. Concept mapping for community perceptions. In: Burke JG, Albert SM, eds. *Methods for Community Public Health Research.* Springer Publishing Company; 2014:171–172.
12. Anderson LA, Slonim A, Yen IH, Jones DL, Allen P, Hunter RH, et al. Developing a framework and priorities to promote mobility among older adults. *Health Educ Behav.* 2014;41(1suppl):10S–18S. doi:10.1177/1090198114537492
13. Mills SL, Bergeron K, Pérez G. Using concept mapping to develop a strategy for self-management support for underserved populations living with chronic conditions, British Columbia, August 2013-June 2014. *Prev Chronic Dis.* 2015;12:E173. doi:10.5888/pcd12.150183
14. Baskin ML, Dulin-Keita A, Thind H, Godsey E. Social and cultural environment factors influencing physical activity among African American adolescents. *J Adolesc Health.* 2015;56(5):536–542. doi:10.1016/j.jadohealth.2015.01.012
15. Walker RE, Kawachi I. Use of concept mapping to explore the influence of food security on food buying practices. *J Acad Nutr Diet.* 2012;112(5):711–717. doi:10.1016/j.jand.2011.12.020
16. Keller AO. A healthy life for African American women caregivers: a concept mapping study. *Womens Health Issues.* 2021;31(2):130–139. doi:10.1016/j.whi.2020.11.011
17. Rosas SR, Kane M. Quality and rigor of the concept mapping methodology: a pooled study analysis. *Eval Program Plann.* 2012;35(2):236–245. doi:10.1016/j.evalprogplan.2011.10.003
18. Kane M, Trochim WMK. *Concept mapping for planning and evaluation.* vol 50. Applied Social Research Methods Series. Sage Publications, Inc; 2007.
19. Key KD, Furr-Holden D, Lewis EY, Cunningham R, Zimmerman MA, Johnson-Lawrence V, et al. The continuum of community engagement in research: a roadmap for understanding and assessing progress. *Prog Community Health Partnersh.* 2019;13(4):427–434. doi:10.1353/cpr.2019.0064

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

20. US Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Healthy People 2030: Social determinants of health. Accessed July 17, 2024. https://health.gov/healthypeople/priority-areas/social-determinants-health
21. Delman J, Arntz D, Whitman A, Skiest H, Kritikos K, Alves P, et al. Using community-based participatory research to conduct a collaborative needs assessment of mental health service users: identifying research questions and building academic-community trust. *Health Promot Pract.* 2024;25(5):855–864. doi:10.1177/15248399231171144
22. Dodgen L, Spence-Almaguer E, Cantu Anguiano K, Hooker A, White S. Partnership processes to develop SHE Tribe: a healthy lifestyle intervention. *Health Promot Pract.* 2020;21(4): 591–600. doi:10.1177/1524839918812428
23. PCORI: Patient-Centered Outcomes Research Institute. The value of engagement. Accessed July 18, 2024. https://www.pcori.org/engagement/value-engagement-research

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table

Table. Community-Driven Solutions, 71 Ideas Within Domains, Milwaukee, Wisconsin, 2016–2021

Domain	Ideas
Alternative modes of transportation	Opportunities for bicycles, fewer cars, high-speed train
Community-engaged public safety	Smoke detectors for homes, police that understand residents' perspectives, police more involved with youth, newsletter from policing units, more police presence, less panhandling, barter system (trade skills and experience)
Health and wellness services	Safe spaces to work out, winter-time fitness options, access to mental health care, health clinic, drugstores, hospitals, farmers markets
High-quality and affordable housing	Higher wages, landlord involvement, owner-occupied homes, take down poorly run apartments, housing stability for renters, resources for homes repairs, affordable and high-quality housing, less homelessness
Investments in young people	Youth centers, childcare, children's recreation programs, playgrounds, summer camps for children
Public infrastructure	Address lead in water, enhanced bus services, neighborhood rideshare program, more street signs, lights at night, control reckless driving, street cameras and doorbell cameras, parking, street repair, trash cans and frequent trash collection
Strong and inclusive neighborhoods	Information about community services, intergenerational programs, people to help elderly, marketing benefits of living in NWS, place to meet with others from NWS, stronger sense of community, community events, support of neighborhood schools, support for neighborhood associations
Sustainable businesses	Opportunities for people of color (Black) to build businesses, more people employed, communication between residents and elected officials, community investments by the city, stronger sense of civic responsibility, communication among residents, funding to improve the area, investment in businesses, middle income families, support from the business community
Vibrant social spaces	Free fiber-optic internet installation, dog park, grocery store, a place for community, swimming pool, access to nutritious foods, coffee shops, community gardens, green spaces, health and wellness programs, restaurants

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE

PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY

Volume 20, E69 AUGUST 2023

ORIGINAL RESEARCH

Creating and Implementing a Community Engagement Strategy for the 2022–2027 Illinois Comprehensive Cancer Control Plan Through an Academic–State Public Health Department Partnership

Leslie R. Carnahan, PhD, MPH[1,2]; Colleen Hallock, MPH, BSN, RN, OCN[2]; Brenda Soto, MPH[1,2]; Linda Kasebier, MPH, MHS[3]; Elise Dracos, BA[3]; Erica Martinez, MBA, MPH[1]; Jennifer Newsome, MS[4]; Tigist Mersha, BS[1,2]; David Pluta, MPH[5]; Vida Henderson, PhD, PharmD, MPH, MFA[6]; Manorama Khare, PhD, MS[5]

Accessible Version: www.cdc.gov/pcd/issues/2023/22_0422.htm

Suggested citation for this article: Carnahan LR, Hallock C, Soto B, Kasebier L, Dracos E, Martinez E, et al. Creating and Implementing a Community Engagement Strategy for the 2022–2027 Illinois Comprehensive Cancer Control Plan Through an Academic–State Public Health Department Partnership. Prev Chronic Dis 2023;20:220422. DOI: https://doi.org/10.5888/pcd20.220422.

PEER REVIEWED

Summary

What is already known on this topic?

Comprehensive cancer control plans are important tools for guiding community and state-level activities that focus on cancer prevention and control by identifying priorities and health equity strategies to address the burden of cancer.

What is added by this report?

The development and implementation of these plans should include community members and people from multiple sectors.

What are the implications for public health practice?

This report provides a model of community engagement that can serve as a blueprint for other statewide cancer coalitions working on their own plans.

Abstract

Introduction

Comprehensive cancer control (CCC) plans are state-level blueprints that identify regional cancer priorities and health equity strategies. Coalitions are encouraged to engage with community members, advocacy groups, people representing multiple sectors, and working partners throughout the development process. We describe the community and legislative engagement strategy developed and implemented during 2020–2022 for the 2022–2027 Illinois CCC plan.

Methods

The engagement strategies were grounded in theory and evidence-based tools and resources. It was developed and implemented by coalition members representing the state health department and an academic partner, with feedback from the larger coalition. The strategy included a statewide town hall, 8 focus groups, and raising awareness of the plan among state policy makers.

Results

A total of 112 people participated in the town hall and focus groups, including 40 (36%) cancer survivors, 31 (28%) cancer caregivers, and 18 (16%) Latino and 26 (23%) African American residents. Fourteen of 53 (26%) focus group participants identified as rural. Participants identified drivers of cancer disparities (eg, lack of a comprehensive health insurance system, discrimination, transportation access) and funding and policy priorities. Illinois House Resolution 0675, the Illinois Cancer Control Plan, was passed in March 2022.

Conclusion

The expertise and voices of community members affected by cancer can be documented and reflected in CCC plans. CCC plans can be brought to the attention of policy makers. Other coalitions working on state plans may consider replicating our strategy. Ultimately, CCC plans should reflect health equity principles and prioritize eliminating cancer disparities.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
VOLUME 20, E69
AUGUST 2023

Introduction

Comprehensive cancer control (CCC) plans are blueprints that identify region-specific cancer priorities and health equity strategies to address cancer prevention and control (1–3). The Centers for Disease Control and Prevention's (CDC's) National Comprehensive Cancer Control Program, established in 1998, supports CCC development and provides funding, guidance, and technical assistance to US territories and freely associated states, the District of Columbia, and tribes and tribal organizations, to design and implement plans (4). Plans guide cancer prevention and control activities with the goal of reducing cancer incidence and death rates by addressing all parts of the cancer continuum (1–3,5). Although including goals, objectives, and strategies is standard across plans, each plan is unique to its region, and content varies in scope, priorities, and length.

Statewide coalitions are responsible for creating CCC plans, and these plans generally span a 5-year period (3). When working on the development of CCC plans, coalitions are encouraged to engage people with diverse perspectives, such as community members, advocacy groups, people representing multiple sectors, and working partners (1,2,5–7). Meaningful community engagement can advance cancer health equity by informing practice, research, and policy with input from people who are typically marginalized and by identifying community-aligned solutions (8).

The Illinois Department of Public Health received funding from CDC to administer the Illinois Comprehensive Cancer Control Program and develop the 2022–2027 Illinois Comprehensive Cancer Control Plan in collaboration with its statewide coalition, the Illinois Cancer Partnership (ICP). The plan identifies how the state will address cancer with a focus on reducing cancer incidence and death rates through prevention, screening, early detection, and diagnosis, treatment, and survivorship, all with health equity–focused activities and strategies. A new addition to the 2022–2027 Illinois Comprehensive Cancer Control Plan is a robust, multipronged community engagement approach.

We describe the community engagement strategy developed and implemented for the 2022–2027 Illinois Comprehensive Cancer Control Plan. This model can serve as a blueprint for other statewide cancer coalitions working on their own CCC plans.

Methods

The process to develop a community engagement strategy for the 2022–2027 Illinois Comprehensive Cancer Control Plan began with a meeting in October 2020 between the state health department partner and the academic partner (Figure 1). The goal of this meeting was to create a partnership that used a health equity lens to engage diverse community members and discuss the resources and assets that each partner was able to provide. Partners identified the following goals, which guided all subsequent activities:

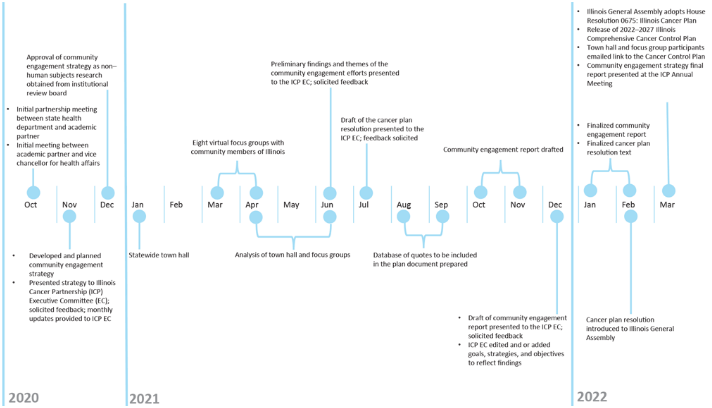


Figure 1. Timeline of activities for creating and implementing a community engagement strategy for the 2022–2027 Illinois Comprehensive Cancer Control Plan.

- **Goal 1:** Develop a strategy to engage diverse perspectives in the development process for the 2022–2027 Illinois Comprehensive Cancer Control Plan.
- **Goal 2:** Elicit community feedback on the plan's goals and objectives, focusing on addressing cancer inequities in Illinois.
- **Goal 3:** Raise awareness of the development of the plan among Illinois legislative and community members, coalition members, and others with a vested interest in addressing cancer needs in Illinois.

The partners completed a partnership agreement template (Appendix) to establish ground rules for collaboration and determine desired level of collaboration, based on the Collaboration Spectrum Tool (9). The levels of partnership include cooperate, coordinate, collaborate, and integrate. The agreement summarized mutual benefits and described alignments with each partner's strategic priorities, guidelines for authorship, and partners' roles and scope of work (Figure 2) (9,10).

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

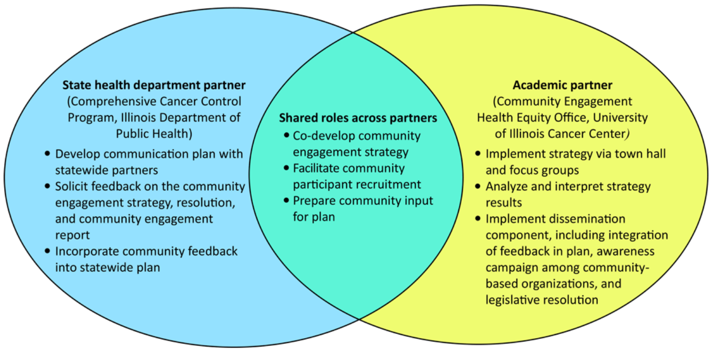


Figure 2. Unique and shared roles and responsibilities of the state health department and academic partners for the community engagement strategy for the 2022–2027 Illinois Comprehensive Cancer Control Plan.

Implementation of the community member engagement strategy

By consensus, partners determined that the community engagement strategy would include a virtual town hall meeting and a series of 8 virtual focus groups. The overall objectives of the town hall and focus groups were to identify 1) cancer-related problems, barriers, and gaps that people in Illinois experience; 2) solutions, facilitating factors, and strengths to address the problems; and 3) funding priorities. The town hall was hosted first, followed by the 8 focus groups that delved deeper into topics about health equity and cancer disparities.

The University of Illinois Institutional Review Board reviewed an application for the determination of human subjects research and granted this project (protocol no. 2020–1552) a formal Determination of Quality Improvement status.

Recruitment and eligibility

We recruited participants for both the town hall and the focus groups primarily through flyers sent via email to the academic and state health department partner networks throughout the state. In addition, flyers were distributed to the ICP listserv of approximately 600 people, including health practitioners and administrators from city, county, and state health departments, and hospitals and community health centers; representatives of cancer advocacy organizations; cancer survivors and caregivers of cancer patients; and researchers and clinicians, all of whom were encouraged to distribute the flyers through their own networks and social media.

The town hall was held during the day in January 2021 and was open to all interested adults residing in Illinois; online preregistration was required. People who completed the registration process received a follow-up email with a link to the meeting, followed by at least 2 reminder emails. We asked town hall participants to indicate their sex, race and ethnicity, whether they were a cancer survivor or caregiver for a cancer patient, and affiliation (eg, community member, hospital, government agency). We did not ask town hall participants to indicate age, health insurance coverage, preferred language, or residence (rural vs urban).

For the focus groups, held in March and April 2021, we used purposive sampling methods to select participants to ensure broad representation based on race and ethnicity, cancer survivors and caregivers, health insurance status, and residence (urban vs rural). Potential participants completed a registration form, which included questions on demographic characteristics (race and ethnicity, sex, age, preferred language, and rural vs urban residence). Rural or urban residency was based on the person's perception of place and not a specific classification system. People were not required to participate in the town hall to sign up for focus groups. Several focus groups were offered in the evening or during the weekend to promote participation among those who may not have availability during the week.

Town hall and focus group procedures

The town hall and focus groups procedures were organized and aligned with CDC's Community Health Assessment and Group Evaluation (CHANGE) Action Guide (11) and the Center for Community Health and Development at the University of Kansas' Community Tool Box (12), both of which provide guidance and best practices for engaging with community members to understand and assess health disparities.

The academic partner developed semistructured moderator guides for the town hall and focus groups (Table 1). The moderator guides were based on a model for the analysis of population health and health disparities (13), which incorporates a multilevel lens to understand factors that contribute to health disparities: fundamental causes, the social and physical context, individual demographics and risk factors, and biologic responses and pathways.

The town hall, which included a breakout session, was hosted by the academic partner and lasted 90 minutes. It was used as an opportunity to raise awareness of the cancer control plan and recruit focus group participants. The town hall began with introductions from the state health department and academic partners. Participants were randomly assigned to 1 of 5 breakout rooms to delve into specific cancer-related topics, with a facilitator and notetaker from the academic partner in each room. After the breakout sessions, participants returned to the town hall and were invited to complete online registration for a focus group.

The academic partner hosted and facilitated the focus groups in March and April 2021. Of the 8 focus groups, 3 were for the general population and each of the other 5 was tailored for a specified

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

group: rural residents, cancer survivors, young cancer survivors, cancer caregivers, and Spanish speakers. All focus groups were recorded and lasted from 75 to 98 minutes (mean, 83 min). On average, each group had 7 participants (range, 5–10). Participants received a $40-equivalent gift (gift card, electronic code, or digital payment) to acknowledge their time and effort and decrease barriers to participation. Before the town hall and focus groups, the academic partner held 3 one-hour training sessions for facilitators to review the basic principles of conducting qualitative data collection, building participant rapport, asking good questions and probes, and managing group conversations.

Analysis of data from town hall and focus groups

The town hall was not recorded because of technical problems in using breakout rooms in the Zoom platform, but a notetaker was assigned to the main town hall Zoom room in addition to the notetakers in the breakout rooms. Immediately after the town hall, the facilitators and notetakers reviewed and discussed notes, organized them topically, and listed key themes.

All focus groups were recorded via Zoom. Before analysis, all focus groups were transcribed, checked for accuracy, and deidentified. We used Dedoose version 9.0.18, a web-based qualitative data software application to conduct analysis. Members of the analytic team (L.C., C.H., B.S.) used content analysis procedures and developed a codebook to identify themes and subthemes. The final codebook consisted of 58 codes. Finally, themes were organized according to the model for analysis of population health and health disparities (13), and sample quotes were extracted to illustrate themes.

At the time of the focus group and town hall, the ICP had already drafted the goals, objectives, and strategies to be included in the 2022–2027 Illinois Comprehensive Cancer Control Plan. The ICP reviewed the major themes identified by the analysis of data from the town hall and focus groups and revised the plan according to this analysis.

Implementation of the legislative body engagement strategy

The academic partner, in consultation with the ICP and the state health department partner, initiated engagement with the Illinois legislative body by drafting a resolution to raise awareness of a state cancer plan and the development of the 2022–2027 plan. A resolution is a statement of opinion that does not have the force of law. Because of rules and laws about lobbying, the state health department partner was not permitted to engage with the legislative body. The academic partner, in consultation with their institution's vice chancellor for health affairs office, whose function is health affairs advocacy and government relations, created the initial draft of the resolution. The draft was then shared with the ICP for input, which was incorporated into the final version. Next, the academic partner, in collaboration with the vice chancellor for health affairs office, contacted the American Cancer Society's director of government affairs for Illinois to leverage their expertise in advocacy and policy work. The academic partner facilitated a meeting between the vice chancellor for health affairs office and the American Cancer Society, wherein it was decided that the next step would be to engage the Illinois Joint Legislative Cancer Caucus to seek support for adoption of the resolution. Finally, a schedule to contact the chair of the Cancer Caucus was set to align with the state's legislative session calendar.

Results

Community member engagement

In total, 112 people participated in the community engagement strategies; 59 (53%) participated in the town hall only, 50 (45%) in the focus groups only, and 3 (3%) participated in both (Table 2). Overall, 102 (91%) participants self-reported their sex as female; 18 (16%) self-reported Hispanic, Spanish, or Latino origin; 26 (23%), Black or African American; 75 (67%), White; and 7 (6%), Asian. Focus groups participants on average were aged 52 (SD, 14; range, 25–88) years. Of 53 focus group participants, 5 (9%) reported a preference for Spanish language, and 14 (26%) were rural residents. Of the 62 town hall participants, 22 (35%) reported an academic affiliation, 10 (16%) reported being from a community-based organization, and 8 (13%) reported being from a hospital or clinical setting.

Major themes from town hall and focus group analysis

Participants in the town hall and focus groups described factors that contribute to cancer disparities among people in Illinois.

The town hall participants discussed the importance of understanding and addressing health disparities broadly and specifically to cancer throughout the CCC plan. One town hall attendee stated, "Cancer affects everyone but not everyone equally." Determinants of health, such as access to food, safe physical activity, transportation, health insurance coverage, access to health care providers (including specialists), treatment options (including second opinions and clinical trials), and knowledge about health, health care systems, and available resources were discussed extensively, especially as they pertained to racial and ethnic groups and immigrant status in Illinois. Participants also discussed how access to transportation and cancer care resources (ie, patient navigators, specialty care), the digital divide, and exposure to environmental hazards depend on where one lives in Illinois. They recommended

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

that the plan include education and awareness of multiple cancer types; highlight the importance of early detection, patient navigation, and collaboration with health systems and organizations; and ensure that goals and objectives are realistic and attainable. Finally, the COVID-19 pandemic was a major topic of discussion, especially concerns about exposure among cancer patients and survivors and disruption of the health care system and cancer care.

Key themes from the focus groups largely mirrored those from the town hall (Table 3). Overall, the lack of a comprehensive health insurance system in Illinois and discrimination based on race and ethnicity and immigration status were identified as being the primary policy and social conditions that contributed to cancer disparities across the cancer continuum. Concerning the institutional context, lack of access to quality systems and services was a recurring theme. Concerning the physical context, participants discussed the importance of where one lives and how place relates to community and individual health outcomes. Specifically, participants discussed environmental hazards, internet access and the digital divide, transportation, and food insecurity as subthemes. Access to health care and transportation challenges were noted among both rural and urban residents, although we found nuanced differences. For example, rural residents talked more about a lack of medical facilities overall, and urban residents talked more about access in terms of quality of care. Furthermore, urban residents noted access to supports and resources that are available to people living in an urban center, whereas rural residents often discussed a lack of resources to address needs across the cancer continuum (ie, education and prevention resources, care navigation services, innovative diagnostic and treatment care, and survivor peer and social support).

Focus group participants also discussed the importance of the social context and how factors such as community poverty, residential segregation, and inadequate social networks contribute to cancer disparities in the state. Rural residents noted their large aging populations and discussed age-related challenges. Participants discussed the effect of individual-level risk factors and health behaviors on cancer disparities, but when they mentioned these, they typically connected these factors with the social and physical community contexts that shape behavior, such as access to resources, safety, and engagement in physical activity.

Recommendations and funding priorities to improve health across the cancer continuum

Participants in the town hall and focus groups recommended policy and systems, clinical, community, and individual-level strategies and funding priorities to address cancer disparities in Illinois. The recommendations spanned the entire cancer care continuum, from prevention, screening, diagnosis, and treatment to survivorship and palliative care. The primary policy concern was ensuring that all who need cancer care are able to receive it, regardless of cost and ability to pay. Clinical-level recommendations to address cancer disparities included access to patient navigation, improved patient–provider communication, and training for health care providers. Community-level recommendations included increased access to community navigators, ensuring that transportation needs are met for both rural and urban communities, and addressing food insecurity by establishing food depositories throughout the state. Finally, individual-level recommendations included the need to increase awareness and education opportunities about cancer.

Town hall and focus group participants shared their ideas about how funds should be prioritized in Illinois to address cancer. First, they noted that community organizations, especially those addressing cancer disparities and working collaboratively, should be prioritized for funding. They also suggested prioritizing funding for cancer prevention and research; programs that provide social, emotional, and educational support; and patient navigation services. Finally, participants mentioned that funding needed to be spread out across different types of cancers.

The complete report on the results of the town hall and focus groups can be found in the 2022–2027 Illinois Comprehensive Cancer Control Plan (14). The report incorporated participant quotes to support specific goals, objectives, and strategies. In addition, 8 infographics were created to support dissemination (15).

Legislative members engagement strategy

The chair of the Illinois Joint Legislative Cancer Caucus agreed to be the primary sponsor of Illinois House Resolution 0675, the 2022–2027 Illinois Comprehensive Cancer Control Plan (16), and garnered cosponsorship from other legislators. The resolution, adopted on March 15, 2022, approximately 1 month after it was filed, urged all legislators to support and promote the plan to address 3 priority areas (prevention; early detection and screening; and diagnosis, treatment, and survivorship) by engaging, educating, and empowering constituents through community engagement. The resolution discusses social determinants of health and recognizes the need to address cancer health equity and eliminate health disparities by providing a framework for strategies and interventions that address structural and systemic barriers.

Discussion

We implemented a robust community engagement strategy through a successful state health department–academic partnership. Our work informed the development of the 2022–2027 Illinois Comprehensive Cancer Control Plan and helped raise

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

awareness of the plan among Illinois legislators. This model of community engagement can be replicated by other coalitions that are developing state cancer plans or other similar documents. Many states are already using similar approaches to prepare their plans. For example, Indiana (17), Nebraska (18), and Tennessee (19) used town halls and focus groups to understand community priorities What is unique about the community engagement approach is that it is explicitly centered in health equity theory, which promotes understanding cancer concerns at multiple levels. Relatedly, many states have described using collaborative approaches that involve multiple partners. However, many descriptions lack details about the various roles and responsibilities involved in planning. Our work described and delineated unique and shared roles and responsibilities of academic and state health department partners.

Using community engagement approaches ensured that the Illinois plan reflects the voices of people affected by cancer in Illinois and the diverse needs and assets in the state. Our approach was guided by public health models of engagement and theoretical models of social determinants of health (11–13). This approach emphasized understanding and addressing not only the role of individual-level risk factors and behaviors in cancer health disparities but also the role of fundamental causes and physical and social contexts. This approach may also be considered for creating strategic plans to address other chronic conditions.

Limitations

Our community engagement strategy has several limitations. First, we did not have a transcription of the town hall meeting, so we were unable to review verbatim comments. However, the academic partner had notetakers for the town hall and for each breakout room. Second, recruitment focused on ensuring representation of participants by rural and urban residence, health insurance status, and race and ethnicity. Thus, the perspective of some populations (eg, men, people with gender identities other than male or female) may be limited. Coalitions could consider recruitment strategies that take this limitation into account. Third, we used self-reported information on rural residency, and a participant's perception of rural residency may not match an objective measure. However, we wanted to acknowledge the validity of lived experiences. Finally, because of the timing of our work and the COVID-19 pandemic, we were unable to have in-person events. Although virtual focus groups have some advantages, such as mitigating travel challenges and reaching diverse populations, virtual modalities are less likely to reach people without access to or the capacity to use technology (20,21).

Conclusion

We recommend that the ICP and other coalitions working on cancer plans develop strategies to include community members in the development of plan goals, objectives, and strategies. Although the 2022–2027 Illinois Comprehensive Cancer Control Plan considered community feedback before these elements were finalized, soliciting this input at the onset would have increased community engagement and participation.

Our community engagement strategy reflects a process through which the expertise and voices of community members can be documented and reflected in state CCC plans. We highlighted a mechanism through which plans can be brought to the attention of legislators. Other coalitions working on their state's plans could consider replicating some or all of our strategy. Ultimately, plans should reflect principles of health equity and prioritize the elimination of cancer disparities.

Acknowledgments

We extend our gratitude to the community members in Illinois who shared their stories and contributed to this work. We also thank the following people for their efforts in planning and implementing the town hall and focus group: Sarah Christian, MPH; Yohana Ghdey, MPH; Jeanette Gonzalez, MS; Le'Chaun Kendall, MPH; Nasima Mannan, MPH; and Ana Williams, MPH, MHA, DDS. Finally, we thank members of the Illinois Cancer Partnership for supporting community engagement efforts for the 2022–2027 Illinois Comprehensive Cancer Control Plan.

The community engagement strategy activities (town hall and focus groups) were supported by the University of Illinois Cancer Center. Funding for the 2022–2027 Illinois Comprehensive Cancer Control Plan was provided by CDC grant DP17-1701 through the Illinois Department of Public Health. The authors take full responsibility for this content and did not receive honoraria or disclose any relevant financial relationships. No copyrighted tools or other materials were used in this research or article.

Author Information

Corresponding Author: Leslie Carnahan, PhD, MPH, University of Illinois Cancer Center, 818 S Wolcott Ave (MC709), Chicago, IL 60612 (lcarna2@uic.edu).

Author Affiliations: [1]University of Illinois Cancer Center, Chicago, Illinois. [2]School of Public Health, University of Illinois Chicago, Chicago, Illinois. [3]Illinois Department of Public Health,

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Springfield, Illinois. [4]Foundation for the National Institutes of Health, North Bethesda, Maryland. [5]Department of Family and Community Medicine, University of Illinois College of Medicine Rockford, Rockford, Illinois. [6]Fred Hutchinson Cancer Research Center, Seattle, Washington.

References

1. Pyron T, Fonseka J, Young M, Zimmerman L, Moore AR, Hayes N. Examining comprehensive cancer control partnerships, plans, and program interventions: successes and lessons learned from a utilization-focused evaluation. Cancer Causes Control 2018;29(12):1163–71.
2. Hohman K, Given L, Graaf L, Sergeant J, Muthukuda D, Devery T, et al. Evolution of comprehensive cancer control plans and partnerships. Cancer Causes Control 2018;29(12):1181–93.
3. Ory MG, Sanner B, Vollmer Dahlke D, Melvin CL. Promoting public health through state cancer control plans: a review of capacity and sustainability. Front Public Health 2015;3:40.
4. Division of Cancer Control and Prevention, Centers for Disease Control and Prevention. About the National Comprehensive Cancer Control Program. National Comprehensive Cancer Control Program (NCCCP). Published July 31, 2021. Accessed November 2, 2022. https://www.cdc.gov/cancer/ncccp/about.htm
5. Vinson CA, Staples C, Shafir S, Given L, Miller N. Collaborating to conquer cancer: the role of partnerships in comprehensive cancer control. Cancer Causes Control 2018;29(12):1173–80.
6. Hayes NS, Hohman K, Vinson C, Pratt-Chapman M. Comprehensive cancer control in the U.S.: summarizing twenty years of progress and looking ahead. Cancer Causes Control 2018;29(12):1305–9.
7. Love B, Benedict C, Van Kirk Villalobos A, Cone JN. Communication and comprehensive cancer control coalitions: lessons from two decades of campaigns, outreach, and training. Cancer Causes Control 2018;29(12):1239–47.
8. Aguilar-Gaxiola S, Ahmed SM, Anise A, Azzahir A, Baker KE, Cupito A, et al. Assessing meaningful community engagement: a conceptual model to advance health equity through transformed systems for health. NAM Perspect 2022;22(2).
9. Tamarack Institute. Tool: Collaboration Spectrum. 2017. Accessed September 1, 2020. https://www.tamarackcommunity.ca/library/collaboration-spectrum-tool
10. Sadeghnezhad M, Heshmati Nabavi F, Najafi F, Kareshki H, Esmaily H. Mutual benefits in academic–service partnership: an integrative review. Nurse Educ Today 2018;68:78–85.
11. Centers for Disease Control and Prevention. Community Health Assessment aNd Group Evaluation (CHANGE) Action Guide: building a foundation of knowledge to prioritize community needs. US Department of Health and Human Services; 2010. Accessed October 7, 2022. https://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/tools/change/pdf/changeactionguide.pdf
12. Center for Community Health and Development at the University of Kansas. Community Tool Box. Accessed October 7, 2022. https://ctb.ku.edu
13. Warnecke RB, Oh A, Breen N, Gehlert S, Paskett E, Tucker KL, et al. Approaching health disparities from a population perspective: the National Institutes of Health Centers for Population Health and Health Disparities. Am J Public Health 2008;98(9):1608–15.
14. Illinois Department of Public Health. 2022–2027 Illinois Comprehensive Cancer Control Plan. 2022. Accessed April 24, 2023. https://dph.illinois.gov/content/dam/soi/en/web/idph/publications/idph/topics-and-services/diseases-and-conditions/cancer/2022-2027_IL-Comp-Cancer-Plan_03092022.pdf
15. Illinois Department of Public Health. 2022-2027 Illinois Comprehensive Cancer Control Plan social media ambassador dissemination toolkit. April 26, 2022. Accessed May 15, 2023. https://dph.illinois.gov/content/dam/soi/en/web/idph/publications/idph/topics-and-services/diseases-and-conditions/cancer/2022-2027_Cancer-Plan-Dissemination-Toolkit_04.26.2022.pdf
16. Illinois Cancer Control Plan, HR 0675, 102nd General Assembly (Ill 2022). March 15, 2022. Accessed April 24, 2023. https://www.ilga.gov/legislation/BillStatus.asp?DocNum=675&GAID=16&DocTypeID=HR&SessionID=110&GA=102
17. Indiana Cancer Consortium. Indiana Cancer Control Plan 2021–2022. Accessed April 24, 2023. https://indianacancer.org/wp-content/uploads/2021/02/FINAL_21-22IndianaCancerControlPlan.pdf
18. Nebraska Department of Health and Human Services. Nebraska Cancer Plan 2017–2022. Accessed April 24, 2023. https://ftp.cdc.gov/pub/Publications/Cancer/ccc/nebraska_ccc_plan-508.pdf
19. Tennessee Department of Health. State of Tennessee Cancer Plan 2018–2022. https://ftp.cdc.gov/pub/Publications/Cancer/ccc/tennessee_ccc_plan-508.pdf
20. Dos Santos Marques IC, Theiss LM, Johnson CY, McLin E, Ruf BA, Vickers SM, et al. Implementation of virtual focus groups for qualitative data collection in a global pandemic. Am J Surg 2021;221(5):918–22.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

21. Rupert DJ, Poehlman JA, Hayes JJ, Ray SE, Moultrie RR. Virtual versus in-person focus groups: comparison of costs, recruitment, and participant logistics. J Med Internet Res 2017;19(3):e80.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Tables

Table 1. Sample Questions From the Moderator Guide for the Town Hall and Focus Groups, Community Engagement Strategy for the 2022–2027 Illinois Comprehensive Cancer Control Plan[a]

Multilevel factor	Description	Sample questions
Fundamental causes	Includes social conditions and policies (eg, poverty, public policy, culture, norms, discrimination) and the institutional context (eg, health care system; economic, legal, political systems).	• Now, I would like you to think about yourself, a loved one, or someone from your community who was diagnosed with cancer. How easy or hard would it be for this person to get the information to make decisions about their care? • How easy or hard would it be for this person to get good, high-quality treatment? • What would make it easier for this person to get the care they need?
Physical and social context	Includes physical context (eg, pollution, transit access, parks), social context (eg, collective efficacy, social capital, racial and ethnic integration), and social relationships (eg, social networks, social support, civic engagement).	• Health disparities are differences that we see in health and health care between groups. These groups can be based on race, where you live, your income level, gender, sexual orientation, age, or physical abilities, among other things. For example, some groups have worse health outcomes related to cancer and less access to care than others. What do you think are some of the things in your community that contribute to cancer disparities? • What are some of the best ways to improve cancer disparities?
Individual demographic characteristics and risk factors	Includes individual demographic characteristics (eg, age, socioeconomic status, health status) and individual risk behaviors (eg, tobacco use, engagement in health care system).	• Would you tell me about a time when you knew you needed to get a recommended cancer screening, but decided not to do it, or put it off for a period of time? • Now, think about a time when you knew you needed to get a cancer screening and you did. What helped you take that action?
Biologic responses and pathways	Includes biologic responses (eg, stress, hypertension, previous illness) and biologic and genetic pathways (eg, allostatic load, genetic ancestry).	• How, if at all, is cancer talked about in your family? • How has this influenced your use of getting screened for different cancers?

[a] The moderator guides were informed by a model for analysis of population health and health disparities (13), which articulates multilevel factors that are important to consider when seeking to understand disparate health outcomes: fundamental causes, the social and physical context, individual demographics and risk factors, and biologic responses and pathways.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table 2. Characteristics of Participants in Community Engagement Strategy (N = 112) for the 2022–2027 Illinois Comprehensive Cancer Control Plan

Characteristic	No. (%)
Participation	
Participated in town hall only	59 (53)
Participated in focus group only	50 (45)
Participated in both town hall and focus group	3 (3)
Sex	
Female	102 (91)
Male	9 (8)
Sex not reported	1 (1)
Hispanic, Spanish, or Latino origin	18 (16)
Race	
American Indian or Alaska Native	1 (1)
Asian	7 (6)
Black or African American	26 (23)
White	75 (67)
Race not reported	3 (3)
Cancer survivor	40 (36)
Caregiver for a cancer patient (current or past)	31 (28)
Affiliation[a]	
Community member	5 (8)
Academic affiliate	22 (35)
Community-based organization	10 (16)
Hospital or clinical setting	8 (13)
Government agency or health department	5 (8)
Age, y[b,c]	
<40	12 (23)
40–59	25 (47)
>60	16 (30)
Current health insurance coverage[b,d]	
Private	33 (62)
Public	14 (26)
Other source of coverage	3 (6)
Uninsured, no coverage	3 (6)
Preferred language for focus group[b]	
English	48 (91)
Spanish	5 (9)
Current rural residence[b]	14 (26)

[a] Question asked only of town hall participants (n = 62); they were asked to select all that apply.
[b] Question asked only of focus group participants (n = 53).
[c] Mean (SD) [range] = 52 (14) [25–88] years.
[d] Public insurance includes Medicare, Medicaid, or coverage through the Affordable Care Act.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table 3. Sample Quotes From Focus Group Participants About Multilevel Factors That Contribute to Cancer Disparities Among People in Illinois, Community Engagement Strategy for the 2022–2027 Illinois Comprehensive Cancer Control Plan

Multilevel factor	Sample quote
Fundamental causes of cancer disparities	
• Access to quality care, clinical trials, patient navigation services • Social conditions and policies, including lack of comprehensive health insurance system • Institutional context, including lack of access to quality systems and services • Discrimination	[Access to a research institution] is literally a lifeline. You have access to clinical trials . . . and the response time is phenomenal if you're in a location that has that kind of infrastructure. But most . . . in this country do not live near a major research hospital. And I do not expect that we can be successful at treating cancer early, or even getting people treatment that they need, without the access. Access is everything. [African American cancer survivor from Cook County, aged 60 years] My insurance is through the Affordable Care Act. When Illinois extended Medicaid to cover low-income individuals, I qualified. And I find having that as my insurance affects who I can see. . . . I feel that the quality of health care I'm getting . . . because of my insurance is less. It isn't as good. [Non-Hispanic White cancer survivor from central Illinois, aged 57 years] And I've heard from friends, in particular, friends who are not White, who do not feel like doctors trust or actually listen to them and validate what they're experiencing. [Non-Hispanic White cancer survivor from Cook County, aged 34 years]
Physical context	
• Location (rural vs urban) • Environmental hazards • Digital divide and telehealth • Transportation • Food insecurity	So, if you're in a hard-to-reach region, why should you get third-tier treatment? It's an unequal distribution of medical care in the state and it has been for a very, very long time. [Non-Hispanic White cancer survivor from rural central Illinois, aged 55 years] I think if one lives in an urban area, your air quality probably isn't very good. So, that probably has a lot to do with cancer diagnoses. [Non-Hispanic White cancer survivor from Cook County, aged 58 years] I mean, not everyone has access to a vehicle. . . . Quite often, the medical profession doesn't consider that. . . . And in a way, it's like blaming the victim because I don't have access to what I need to get there. . . . Access for me is difficult. And somehow, they never seem to ask those questions. You know, what can we do to help you get here? Do you need a ride? Something like that. None of that becomes a conversation. [African American cancer survivor and caregiver from central Illinois, aged 49 years]
Social context	
• Fear of cancer in communities • Community characteristics • Residential segregation • Social networks and norms • Patient–provider relationships	I think part of it is the fear of the expense of medical care, not understanding it — having insurance or not, understanding insurance, and that financial fear. [Asian cancer survivor and caregiver from Cook County, aged 63 years] Having a conversation with the doctor may not be as understandable, and people don't know how to continue to say, "I don't understand" or "tell me in a different way." So, it's also a point of literacy and understanding. So, the doctor went to medical school and he or she is an expert. But if they can't deliver that message and that information in a way that's understandable, then they haven't done a good job. And so, I may sit in the office, I may get lots of information which is good pertinent information. But if I don't understand it, I don't have anything. [African American cancer survivor and caregiver from central Illinois, aged 49 years]
Individual demographics, risk factors, and biologic responses and pathways	
• Insurance status • Immigration status	You know, I'm blessed to have a husband, and I've told him many times that were it not for our insurance coverage, I don't know where I'd be. Ovarian cancer is a very expensive treatment. CT scans are 12,000 dollars sometimes. I just don't know how people could do it if they were not covered. I really don't. [Latina cancer survivor and caregiver from Cook County, aged 48 years] There's a lot of people who have the thought that [name of public hospital] isn't good because that's where all of the immigrants go, but . . . people who don't have resources to go to another hospital go there, and that's why they take a long time. Personally, I can say that years ago it was like that. . . . They gave me an ultrasound [appointment] in 6 months. When I got to 6 months, I didn't have the pain anymore. [Latina community member from Cook County, aged 48 years] Once we found out there was a genetic mutation in the family — so now, one of my cousins who's younger than me, she actually got screened for it and so she's talking to a specialist to see what her options are so that she has more of a choice with it. [Non-Hispanic White cancer survivor from rural southern Illinois, aged 36 years]

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Appendix. Text of Community Engagement and Health Equity Office Community Partnership Agreement

This agreement is between The Community Engagement and Health Equity (CEHE) Office, as a part of the University of Illinois Cancer Center and [community organization], each wishing to establish a working relationship to support [Project Work].

[Community organization/partner] and CEHE wish to enable a [level of partnership] partnership and exchange in the Project Work by working together agreeing to the below:

1. Background. [Provide a brief background of the relationship between the partners.]

- Include each organization’s mission
- List who the primary contacts are:
- CEHE primary contact/principal investigator/lead staff
- Community organization/partner

2. Goals of partnership. This agreement reflects the genuine intentions to form a working relationship. The purpose of this agreement is to advance the ideas and activities to meet the following goals:

- Goal 1:
- Goal 2:
- Goal 3:

3. Summary of mutual benefit.

- Based on Give/Get model

What contributions and benefits can the community organization and the community engagement cancer center team share to [work together on (ie, develop or create a plan)] to reach [goals (ie, increase cervical cancer awareness)]

What community can give? What community can get?

What CEHE can give? What CEHE can get?

- What is the alignment with CEHE’s strategic priorities?
- What is the alignment with community organization’s strategic priorities?

4. Authorship and acknowledgments.

- List and order of authorship must be discussed before the development of any manuscripts as a result of the partnership.
- Products as a result of this partnership should include an acknowledgment of the Community Engagement and Health Equity Office at the University of Illinois Cancer Center. Products and publications include research and technical papers, preprints, conference and academic presentations, theses and dissertations, journals and books, oral histories, video and audio recordings of speeches and events, photographs, and key project documents.
- Both partners should be branded together with their respective logos on any promotion or dissemination.
- Partners agree that ownership of intellectual property rights generated as a result of the activities under this agreement will follow inventorship rule and remain the property of the partner introducing and/or disclosing the same to the other partner.

5. Description of engagement deliverables and timeline (scope of work).

Include activities/deliverables, persons responsible for conducting each activity and timeline for completion

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

6. Mutual agreement time period.

- This agreement will remain in effect for one (1) year from the date of the last signature. Either partner may terminate this agreement by informing the other partner with an electronic or written form of communication.

7. Evaluation.

- The partners will convene twice a year to focus discuss partnership status, communication and outcomes

Signed for and on behalf of:

By: [Community organization/partner] [Title]

Date:

By: [CEHE] [CEHE authorized official] [Title]

Date:

AGREEMENT is effective for one year after last signature has been provided; date: ________________

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 17, E12 FEBRUARY 2020

IMPLEMENTATION EVALUATION

Integrating Culture and History to Promote Health and Help Prevent Type 2 Diabetes in American Indian/Alaska Native Communities: Traditional Foods Have Become a Way to Talk About Health

Lemyra DeBruyn, PhD[1]; Lynne Fullerton, PhD[2]; Dawn Satterfield, PhD, RN[3]; Melinda Frank, MPH, LMSW[1]

Accessible Version: www.cdc.gov/pcd/issues/2020/19_0213.htm

Suggested citation for this article: DeBruyn L, Fullerton L, Satterfield D, Frank M. Integrating Culture and History to Promote Health and Help Prevent Type 2 Diabetes in American Indian/Alaska Native Communities: Traditional Foods Have Become a Way to Talk About Health. Prev Chronic Dis 2020; 17:190213. DOI: https://doi.org/10.5888/pcd17.190213.

PEER REVIEWED

Summary

What is already known on this topic?

Historical, economic, social, and environmental determinants of health are critical to understanding type 2 diabetes in American Indian and Alaska Native communities.

What is added by this report?

Integrating history and culture, 17 tribes and tribal organizations worked during 2008–2014 to increase and sustain community access to traditional foods to promote health and help prevent type 2 diabetes. In partnership with a federal program and each other, tribal partners evaluated community-based interventions locally and across their culturally and geographically diverse communities to demonstrate effectiveness.

What are the implications for public health practice?

Traditional healthy foods and food sovereignty are valuable areas for American Indian and Alaska Native communities to address chronic disease, specifically type 2 diabetes.

Abstract

Purpose and Objectives

The purpose of the Traditional Foods Project (TFP) was to implement and evaluate a community-defined set of strategies to address type 2 diabetes by focusing on traditional foods, physical activity, and social support. The TFP sought to answer 2 questions: first, how do we increase and sustain community access to traditional foods and related activities to promote health and help prevent type 2 diabetes? Second, how do we evaluate interventions across culturally and geographically diverse communities to demonstrate success?

Intervention Approach

Public health interventions are most effective when communities integrate their own cultures and history into local programs. The food sovereignty movement among American Indians/Alaska Natives and indigenous populations globally offers ways to address public health issues such as chronic diseases like type 2 diabetes. Historical, economic, social, and environmental determinants of health are critical to understanding the disease.

Evaluation Methods

During 2008–2014, seventeen tribal TFP partners implemented locally designed interventions and collected quantitative and qualitative data in 3 domains: traditional foods, physical activity, and social support. Partners entered data into a jointly developed evaluation tool and presented additional program data at TFP meetings. Partner observations about the effect of the TFP were gathered in planned discussions.

Results

Quantitative results indicate collaborative community engagement and sustained interventions such as gardening, availability of healthy foods across venues, new health practices, health education, and storytelling. Qualitative results demonstrate the importance of tribally driven programs, underscoring the significance of traditional foods in relation to land, identity, food sovereignty, and food security.

Implications for Public Health

Traditional foods and food sovereignty are important areas for American Indian/Alaska Native communities to address the pub-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

lic health issues of chronic disease, specifically type 2 diabetes, locally and nationwide.

Introduction

Diabetes is highly prevalent in the United States and is associated with increased risk of health problems such as vascular diseases (eg, heart disease, stroke), chronic kidney disease, and blindness (1). It is the seventh leading cause of death in the United States and affects more than 30 million Americans; an additional 84 million adults have prediabetes, and thus are at risk for diabetes (1). Although not all diabetes is preventable, type 2 diabetes, which accounts for 90% to 95% of all diabetes cases, can sometimes be prevented by maintaining a healthy diet, a healthy weight, and a healthy level of physical activity (2). The prevalence of diabetes among US adults has been stable for approximately 10 years, but this is not true of children, adolescents, and young adults (3). A study comparing the prevalence of diabetes among children, adolescents, and young adults (aged <20 y) from 2001 and 2009 found large increases in the prevalence of both type 1 (30.0%, from 1.48 to 1.93 per 1,000 persons) and type 2 (35.0%, from 0.34 to 0.46 per 1,000 persons) diabetes (3). Health complications in this age group are common. In a study of children and adolescents who had a diagnosis of diabetes for at least 5 years, data collected during 2011–2015 showed that 32% with type 1 and 72% with type 2 had at least 1 health complication related to the function of kidneys, eyes, the heart, and the nerve and circulatory systems (4).

Diabetes is not equally distributed among US racial and ethnic groups. The rate of diagnosed diabetes among American Indian/Alaska Native (AI/AN) adults in 2013–2015 (15.1%) was twice the rate among non-Hispanic white adults (7.4%) (5). Disparities among young people are greater. The incidence of type 2 diabetes among AI/AN children, adolescents, and young adults aged 10 to 19 years in 2011–2012 (46.5 per 100,000 population) was more than 10 times the incidence among their non-Hispanic white counterparts (3.9 per 100,000 population) (1). This disparity may be related in part to differences in obesity rates, a known diabetes risk factor. In 2015–2016, the prevalence of obesity among non-Hispanic white children, adolescents, and young adults aged 2 to 19 years in the United States was 14.1% (6). Among AI/ANs of the same age in 2015, the prevalence was 29.7% (7).

The history of type 2 diabetes in the United States illuminates complex issues. The transition from local, harvested foods to foods dense in calories and fat fueled rates of type 2 diabetes and related chronic conditions (8). After World War II, with the shift to a wage economy (9), Americans began to consume readily available processed foods high in sugar and fat and low in fiber and were typically less physically active than before. Rates of diabetes in the United States rose from less than 1% in 1958 (~500,000 people) to 9.4% in 2015 (30.3 million people) (1). Diabetes was also rare among AI/ANs before 1940. Among AI/ANs, as among other Americans, the dramatic changes in diet and declining physical activity preceded rising rates of the disease (8).

Focusing on biologic factors alone overlooks factors that propel development of chronic diseases (10–12). Recognizing historical, economic, and environmental contributions, or social determinants of health, is critical to understanding the trajectory of type 2 diabetes (13,14).

Current social determinants of health associated with development of type 2 diabetes include poverty (15), attaining less than a high school education (5,16), physiologic stress responses associated with historical trauma (17), and adverse childhood experiences (18–20). Food insecurity, defined as uncertain or limited access to enough food for a healthy life, is also correlated with increased risk of developing type 2 diabetes (21). Rates of food insecurity among AI/AN children are approximately 2 times national rates (22). In 2016 nearly 30% of AI/AN households were food insecure, compared with 16% of non-AI/AN households (23,24).

For tribal nations, gathering, planting, or hunting food was integral to physically active and spiritual lives (25). Decades of federal mandates affected the land and water resources of tribal nations, which in turn profoundly disrupted indigenous food systems and reduced access to traditional foods (9,13,25–32). Native peoples in the United States were forced to move and had to adjust to different lands, climates, and the foods they could raise and gather. These foods were often supplemented by government provisions to stave off starvation and malnutrition resulting from disrupted food systems (33,34).

Since the 1970s, federal food distribution programs have provided commodity foods to AI/AN communities (34). These processed foods, high in salt and fat, and demanding very little physical activity to access, often result in what Indian people call a “commod bod” (a “commodity body,” or a body type resulting from consuming commodity foods) (35). Furthermore, food assistance programs alone do not substantially improve food insecurity (24). Some traditional foods (bison, blue corn meal, wild rice) were added recently to food assistance programs, but these foods are not regularly available (34). Access to healthy food across Indian Country is further thwarted by distance (food deserts), limited transportation, inadequate supermarkets, environmental contamination, and little money to purchase healthy foods (31,33,34).

Tribally driven approaches to understanding these issues in Indian Country include indigenous science, sometimes called traditional ecological knowledge, a natural science grounded in lifetimes of

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

observation, experimentation, and adaptation (36). A blueprint for a way of life that has survived (37), traditional ecological knowledge is inextricably linked to traditional foods and food sovereignty. It informs cultivating, harvesting, and sharing foods; storytelling; games; and traditional wisdom (eg, “water is life”) (13). Mihesuah and Hoover recently underscored the connection of food sovereignty to cultural knowledge, environments, and health (33).

The objective of this study was to describe our evaluation of a program designed to promote access to and integrate traditional foods, physical activities, and social support in semistructured ways into culturally and geographically diverse AI/AN communities. The Traditional Foods Project (TFP) provided modest funding and support to 17 AI/AN communities who designed their own interventions to meet the needs of their communities. Stories describing the innovative approaches based on traditional foods, culture, and history to prevent type 2 diabetes among TFP communities have been published elsewhere (13,14,26–30).

Purpose and Objectives

The purpose of the TFP was to promote access to traditional foods, physical activity, and social support to address community health in AI/AN communities, particularly type 2 diabetes prevention. We sought to answer 2 questions. First, how do communities increase and sustain access to traditional healthy foods, physical activity, and social support to promote health and help prevent type 2 diabetes? Second, how do culturally and geographically diverse AI/AN communities, locally and in partnership with one another and a federal program, successfully evaluate interventions?

TFP objectives were to 1) support sustainable, evaluable ecological approaches to reclaim traditional foods, 2) encourage local practices to increase access to healthy traditional foods and physical activity, 3) revive and create stories of healthy traditional ways, and 4) integrate culture and history to promote community health and help prevent type 2 diabetes.

Intervention Approach

The TFP evolved from the findings of earlier projects where traditional foods emerged as a way to promote health and help prevent type 2 diabetes. The Indian Health Service Tribal Leaders Diabetes Committee had suggested looking to tribal cultures to promote health and prevent type 2 diabetes among AI/ANs (13,14). These projects demonstrated that public health interventions are most effective when communities integrate their own cultures and history into local programs (13,14,38,39).

Community-based participatory research is the foundation of the TFP. In community-based participatory research, culture and context are legitimate foci for interventions (40), and partnering with communities in program design, evaluation, and reporting criteria is fundamental (40,41). Community-based participatory research methods were shaped by tribally driven participatory research (41) and framed by food sovereignty — the right of people to define their own policies and strategies for sustainable production, distribution, and consumption of food (34,42).

Evaluation Methods

The TFP used both quantitative and qualitative evaluation methods. Mixed methods were critical to demonstrate which elements of each intervention worked (quantitative measures) and why and how communities became engaged across programs (qualitative measures). Honoring local knowledge and traditions, TFP partners catalyzed their communities such that farmers, health care providers, tribal leaders, subsistence gatherers, administrators, evaluators, and community members came together for the shared purpose of improving community health. Each TFP partner had a local coordinator and evaluator who developed community-supported programs and collected data in 3 domains: traditional foods, physical activity, and social support. All domain interventions were designed to improve health with the long-term goal of helping prevent type 2 diabetes.

Setting and participants

The project began in 2008 with 11 tribes and tribal organizations and was expanded to 17 in 2009. The 17 TFP partners were culturally and geographically diverse. Each partner received $100,000 per year. In 2012, the Centers for Disease Control and Prevention’s Tribal Advisory Committee recommended a sixth year to increase capacity and sustain local efforts. Sixteen of 17 partners applied for and participated in the sixth year at the same level of funding (13).

The initial 11 TFP partners participated in all 5 years of data collection. Five of the 6 partners added later participated in 4 years of data collection. The remaining partner collected data for 3 years but did not participate in the final year.

Procedures

The first year of the TFP focused on program and evaluation planning. Partners who launched the TFP in 2008 began gathering and reporting data in 2009, and partners who joined in 2009 began gathering and reporting data in 2010. Two 6-month data collection periods took place each year, resulting in 10 data collection periods and a sample size of 156 data points for each variable. Odd-numbered periods (T1, T3, T5, T7, T9) corresponded to data

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

collected from October to March, including winter, when gardening was not possible in some communities. Even-numbered periods (T2, T4, T6, T8, T10) corresponded to data from April through September, including summer.

TFP partners reported on local activities and evaluation outcomes in 2 ways. First, partner evaluators entered local data addressing the 3 domains every 6 months into a shared data elements (SDE) tool developed jointly by the Native Diabetes Wellness Program and TFP grantee partners. The SDE was approved by the Office of Management and Budget (OMB no. 0920 0889). Having 2 collection periods during each intervention year allowed for seasonal analyses of partner activities. SDE data included quantitative information about overall numbers of activities across domains as well as numbers of participants, numbers of persons affected (through social media, local radio, and television), and brief qualitative descriptions of grantee partner activities. We gathered no individual health data for aggregate analysis because of cooperative agreement restrictions and the TFP focus on community health. Second, partners presented information on local program interventions, evaluation methods, and findings at TFP meetings either once or twice a year. Quantitative measures included number and size of gardens, weight and types of produce yields, and number of participants in organized physical activities. Qualitative data included stories used for teaching, descriptions of community responses, and examples of how culture and history were integral to TFP activities.

The Native Diabetes Wellness Program evaluation team aggregated and analyzed quantitative SDE data, with TFP partner program and period as the unit of analysis. We returned grantee-specific data to each partner along with aggregated SDE results after each data collection period. We also presented SDE data updates at every meeting.

We collected qualitative data by using the SDE and in other ways. The SDE used open-ended text fields of 50 to 250 characters to describe activities under general categories such as “gardening,” “health education,” and “measures of participant change.” Additionally, we encouraged TFP partners to collect other local data, such as stories. We also gathered partners’ written and oral comments during semi-annual or annual meetings and monthly conference calls.

Intervention framework

The Native Diabetes Wellness Program did not prescribe methods of community intervention for the partners. Each TFP partner used various strategies aimed at behavior changes related to TFP goals. Overall intervention components were unique to each group. Components also differed over time, so the interventions implemented by a partner during, for example, the fourth period were likely different than its activities during the seventh period. Most partners engaged in 1 or more activities in each domain during each period.

Some program components affected more than 1 domain. For example, activities included in gardening or subsistence categories often involved physical activity and/or social support as well as traditional foods. For each activity, partners recorded which domain(s) they considered relevant to each project component.

Measures

Each partner had flexibility to create and implement interventions consistent with local ways, based on local definitions of traditional healthy foods, physical activity, and social support. Traditional foods activities could include gardening, subsistence gathering, hunting, and fishing. Physical activity interventions focused on organized physical activities and places to conduct physical activity programs. We defined social support as any time local participants gathered to support each other, regardless of focus. General categories such as health education, health practices and policies, and storytelling were interventions across all domains.

Quantitative data analysis

We stratified descriptive analyses by period and tabulated frequencies for categorical variables. Denominators used in percentages varied according to period, because the number of partners varied from 11 to 17. We tabulated numeric variables as counts, sums, measures of central tendency, and maximum values. The denominator used to calculated mean and median values for all 10 periods was 156. For many activities, TFP partners recorded the number of participants, the number of new participants, and the number of people affected in each period. We calculated total number of participants for individual activities across partner groups by period. We did not calculate sums of participants across periods, because we had no way to determine the amount of participant overlap between activities or across time.

We examined changes in the prevalence of all activities over time and used simple regression or the χ^2 test for trend. The 156 data points collected were not independent, because groups were represented up to 10 times. We considered a repeated measures analysis but did not use it because the assumptions were not satisfied. For this reason, our analytic statistics examined trends but not relationships between outcomes. We used Stata version 13 (StataCorp LLC) for all analyses.

Qualitative data analysis

The Native Diabetes Wellness Program reviewed SDE qualitative data after each data collection period. We also reviewed local qualitative data such as digital stories and other cultural applica-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

tions of the 3 domains. We analyzed TFP partner evaluation forms and meeting and conference call notes for major themes and illustrative quotes. TFP partners reviewed the themes and quotes to ensure accuracy and intended voice.

Results

Quantitative findings

From 81.8% (9 of 11) to 94.1% (16 of 17) of TFP partners reported gardening activities during summer periods, and 58.8% (10 of 17) to 82.4% (14 of 17) during winter periods (Table 1). Garden types included school, community, family, and program gardens. Community gardens were reported by 37.5% (6 of 16) to 64.7% (11 of 17) of TFP partners for all periods (except T1, when the question about community gardens was not asked). The total number of all gardens increased over time, and ranged from a low of 13 gardens in T1 to a maximum of 510 gardens in T6 (n = 10 periods; controlling for season, $r^2 = 0.85$; coefficient = 25.9; $P = .001$). In T10, TFP partners reported 415 gardens, which covered an area of 28.4 acres, up from 206 gardens and 11.1 acres in T2 (the question about garden acreage was not asked in T1). Numbers of participants were highest for school gardens. For example, in T10, the 6 communities that had school gardens involved 3,017 people.

Reporting on traditional healthy food outlets such as health fairs increased from 18.2% (2 of 11) in T1 to 68.8% (11 of 16) in T10. Access to healthy food at other venues also improved over time. By T10, nearly two-thirds of partners (62.5%; 10 of 16) reported that healthy food selections were available at 1 or more of the following venues: worksites, agencies, supermarkets, vending machines, and restaurants. More partners reported healthy food choices at worksites (37.5%; 6 of 16 in T10) and supermarkets (31.2%; 5 of 16) than at vending machines (6.3%; 1 of 16) and agencies (6.3%; 1 of 16) (Figure 1). Increases in the proportion of partners reporting access to healthy foods over time were significant for healthy foods available at restaurants (χ^2 test for trend = 6.9; $P = .008$) and supermarkets (χ^2 test for trend = 6.0; $P = .01$).

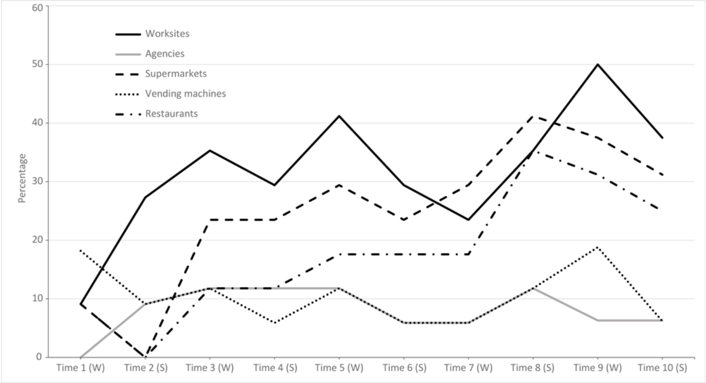


Figure 1. Percentage of partners reporting healthy food selections at worksites and other venues over time, Traditional Foods Project, October 2009–September 2014. Percentages are based on the following denominators: 11 partners participated during T1–T2; 17 partners during T3–T8; and 16 partners during T9–T10. Abbreviations: S, summer; W, winter.

Storytelling was an important teaching activity for most TFP partners in every period; for example, 14 of 16 (87.5%) in T10 reported 1 or more storytelling activities. Most incorporated 1 or more types of storytelling (eg, narrative, digital, music) into program activities (Table 2). The highest proportions of storytelling activities were in the traditional foods domain, ranging from 52.9% (9 of 17) in T7 to 82.4% (14 of 17) in T3. Narrative storytelling activities were the most prevalent (mean, 58.3%, or 91 of 156 samples, over all periods), followed by digital (mean, 37.2%, or 58 of 156).

Most TFP partners reported health education activities for each period (range, 76.5% [13 of 17] in T7 to 100% [11 of 11] in T2). Individual TFP partners reported implementing up to 180 health education activities in a 6-month period (T10) and involving a maximum of 10,900 participants (T5).

TFP partners reported implementing new health practices (including behaviors, resolutions, policies, and other practices not done before) during each 6-month period at an overall rate of 43.6% (68 of 156 total data points), with a maximum of 58.8% (10 of 17 partners) in T5. The total number of new health practices over all groups for any 1 period ranged from 12 (T1) to 78 (T5). As an example, 1 partner reported that their after-school/summer camp implemented a policy that included not having sugar-sweetened beverages and candy available for purchase. In another, Head Start organizations added physical activities, gardening, and a health education curriculum to their programs.

Most partners reported including organized physical activities in their programs (overall average for all periods, 60.9%, or 95 of 156). As many as 7,500 participants were involved in organized

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

physical activities for an individual TFP partner during 1 period (T3). Examples of organized activities included traditional games such as stickball, fun runs, restoration work, canoeing, and dancing.

Partners measured participant changes such as weight loss, improved levels of physical activity, and healthy food choices in 69 of 156 data points recorded during 10 periods. In most periods, almost half (median, 47.1; 8 of 17) of partners were measuring participant change in 1 or more domains (Table 1). Numbers of participants who made changes increased from T1 to T10 for each of the 3 domains, with a maximum at T6 in physical activity (n = 1,388 participants) and social support (n = 1,950 participants) and a maximum at T8 in traditional foods (n = 2,152 participants).

Almost all TFP partners reported collaboration with other agencies in all 10 periods. The proportion of partners reporting at least 1 type of collaboration ranged from 87.5% (14 of 16 in T10) to 100% (11 of 11 in T1; 17 of 17 in T5 and T8; and 16 of 16 in T9). Collaboration was reported most often in the traditional foods domain (89.7% of partners; 140 of 156 overall for the 10 periods), and by most grantees in the physical activity (59.6%; 93 of 156) and social support (56.4%; 88 of 156) domains. Resources shared included staff (71.8%; 112 of 156), space (60.3%; 94 of 156), educational materials (59.6%; 93 of 156), traditional foods (55.1%; 86 of 156), marketing materials (44.9%; 70 of 156), and financial support, such as vouchers (40.4%; 63 of 156).

Media outreach events and materials were described in 103 of 156 (66.0%) reports. In T10, 16 partners conducted 308 media outreach events, developed and distributed 9,264 materials, and affected 31,400 people with media materials. In T1, when programs were just getting started, media was even more commonly reported. The 11 partners reported 1,614 media outreach events at which 77,523 media materials were distributed and 278,235 people affected.

In T10, 56.2% (9 of 16) of TFP programs reported implementing environmental changes in 1 or more domain areas that were designed to be sustainable. Sustainability was also evidenced in activities reported in every period, eg, planting and gardening, particularly community gardening (ranging from 37.5% [6 of 16] to 64.7% [11 of 17] partners). Other examples of sustainable environmental changes included using heirloom seeds, composting, developing health education activities and materials, implementing media outreach activities, implementing health policies and health practices, and collaboration with other agencies (Table 1) .

Qualitative findings

Qualitative data portrayed the role of traditional foods in ways quantitative data could not. The data describe partner perspectives about traditional foods, how well the TFP worked, and why. Results indicate that grantee partners embraced the TFP's community-based, tribally driven approach. Themes and quotes underscore quantitative findings, such as participation, collaboration, and number of gardens (Table 3).

The following examples of tribal partner experiences further illustrate the 7 main themes. The examples usually include more than 1 theme, demonstrating not only their interconnectedness but also how difficult it was for us to separate them.

Traditional knowledge and grassroots. Local elders remarked that corn did not grow very high in their community's desert soil. The TFP coordinator took a course to become a Master Composter, balancing traditional ecological knowledge and western science. He created a compost pile to be used in the community garden to increase produce production. In addition to other compost materials, tribal leaders provided an endless supply of discarded paper and coffee grounds (Figure 2). Community members, particularly the elders, were impressed with how tall the corn grew and marveled at the large yields of harvested produce from the garden.

Figure 2. The compost pile was created to increase produce yield in the community garden, Traditional Foods Project, October 2009–September 2014. Compost materials included paper and coffee grounds provided by tribal leaders, Ramah Navajo, 2011. Photo courtesy of Randy Chatto.

Connections to health. TFP partners inspired the title of this article. "Traditional foods have become a way to talk about health" was a thread in every discussion. Partners could not underscore enough that chronic disease is deeply connected to social determinants of health, such as historical trauma, adverse childhood experiences, and loss of traditional foodways. The way to reclaim health, they said, is to reconnect with the land, water, traditional foodways, and all that they mean.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

The power of stories and storytelling. Narrative stories — oral tradition — were most prevalent compared with other types of stories reported (Table 2). However, TFP partners enthusiastically produced digital stories after learning from another partner how to create them. In turn, they shared the skill with their own people. One story was by a young rapper who had struggled with identity and substance abuse. He "found himself through connection with the earth" in the community garden. He created his digital story to welcome all partners, skillfully rapping their names, at a TFP meeting.

Community engagement. Meetings hosted by TFP partners provided settings for sharing traditional foods, cultural ways, and physical activity. One of the most anticipated activities was the traditional game of stickball. The community was invited to participate or observe (and cheer). Stickball literally created a level playing field, where TFP partners, Native Diabetes Wellness Program team members, and community members, women against men, enjoyed a physically strenuous, humor-filled game.

Knowledge sharing and gratitude. Dynamic exchange of knowledge demonstrated partners' engagement with each other. They shared skills (how to create digital stories), traditional foods (meeting hosts always prepared a feast), and gifts (heirloom seeds, wild rice). Partners were grateful for being able to openly express the meaning of traditional foods and spend time together.

Flexibility to do what works. At the request of grantee partners, we held a discussion on health policy in the second year of the TFP. Partners stated that measuring health policy only was unacceptable: "written policies tell people what to do." Health practices, however, "are chosen by the people because they are good ideas and reflect traditional knowledge." Subsequently, we measured both health policies and health practices.

Program sustainability. TFP partners regularly addressed sustainability, particularly toward the end of the TFP. Most partners (11 of 17) sustained some or all activities after the TFP ended in September 2014. Partners secured funding from tribal councils, university partnerships, state and county health departments, federal agencies, or nonprofit organizations (13).

Implications for Public Health

The TFP's challenge was to answer 2 questions: How do communities increase and sustain access to traditional healthy foods, physical activity, and social support to promote health and help prevent type 2 diabetes? And, how do we, in partnership with one another, successfully evaluate community-based interventions?

Increasing and sustaining access to traditional foods depends on strong local support, collaboration, and traditional knowledge (25–30,33). Grantee partners believed that traditional foods programs can be sustained if the following conditions are met:

•First, human and financial resources are necessary. A local natural leader, knowledgeable about traditional foods and supported financially, is vital.

•Second, tribal leadership support is needed. Where tribal leadership was not supportive, TFP programs were less productive. In contrast, strong backing by tribal leadership contributed to project endurance.

•Third, sustainability is likely when programs are relevant and meaningful. Local decisions about program content, including what constitutes traditional foods, are critical.

•Fourth, collaborating with programs that have related goals strengthens community infrastructure. Partners noted that, over time, other programs sustained activities originated by the TFP.

•Fifth, communities with few resources need time to grow infrastructure. Among TFP partners, small communities demonstrated change quickly but, without strengthened infrastructure, changes were temporary.

Tribally based health promotion efforts to address access to traditional foods in Indian Country are described in the 2015 report, *Feeding Ourselves* (34). Our conclusions are consistent with those described in the report in the section "Case studies: lessons learned and challenges faced by grassroots, nonprofit and tribal food access and health innovators." As an example, the Communities Creating Healthy Environments program addressed childhood obesity by changing communities rather than focusing on individual behaviors, incorporating aspects such as food inequity, safe places for play, and the social environment. The program noted not only the need for local partners but also the need for ongoing support to "implement victories, consolidate gains, and plan next steps" (34).

For our project to be successful, forging trust among TFP partners and the Native Diabetes Wellness Program was paramount (40). Further, equal funding, regardless of community size, gave every program equal voice. In the end, relationships were everything (13,14,26–30,33,34,40).

TFP data did not include aggregated health measures for individual participants (eg, weight change over time) because of funding restrictions and the focus on environment and community. Future TFPs would benefit from tracking changes in individual health outcomes across communities. Collecting local health data may be challenging, however, because of the sensitivity of personal health

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

information. Tribal nations are particularly cautious about sharing personal health data because of their experiences with data misuse (40,43). This history underscores the critical importance of a tribally driven participatory approach (41), where tribes steer the agenda in partnership with the funding entity to develop the program, choose local and aggregate evaluation measures, and select outcomes.

Population sizes and geography varied widely among participating communities. TFP partners used intervention combinations designed for local conditions that could not be directly compared across sites. Environmental factors also made it difficult to compare certain interventions, such as gardening, because some communities had longer growing seasons than others.

We did not conduct bivariate analyses of the relationships between interventions and outcomes (eg, gardening activities and health policy changes). The project was not designed to imply such causal relationships.

It is methodologically challenging to distinguish effects of a particular program when multiple agencies work together. However, working collaboratively makes any single program, and subsequent community infrastructure, stronger.

The TFP addressed physical activity, social support, and healthy diet, factors associated with individual and community health. Partners developed local programs, framed in local cultural, historical, and environmental contexts, which included social determinants of health. Activities incorporated traditional ecological knowledge and western science, illustrating the integral relationship of traditional foods with community history, culture, and health. The TFP demonstrated that tribally driven programs, guided by traditional knowledge, can facilitate access to traditional foods as part of community health interventions to address chronic disease.

"Traditional ways of knowing" have, for generations, linked physical and spiritual health to traditional foods (9,25–30,34,44). The concept is far from new. What is new is the burgeoning food sovereignty movement that reclaims traditional foods in relation to tribal sovereignty, food security and, in this instance, public health. Traditional foods have become, once again, a way to talk about health.

Acknowledgments

Seventeen tribal partners were the cornerstone of the Traditional Foods Project (2008–2014). They are part of the indigenous food sovereignty movement sweeping the globe. To our partners, with gratitude: Aleutian Pribilof Islands Association; Catawba Cultural Preservation Project; Cherokee Nation; Confederated Tribes of Siletz Indians; Eastern Band of Cherokee Indians; Indian Health Care Resource Center of Tulsa; Nooksack Indian Tribe; Prairie Band Potawatomi Nation; Ramah Navajo School Board; Red Lake Band of Chippewa Indians; Salish Kootenai College; Santee Sioux Nation; Sault Ste Marie Tribe of Chippewa Indians; Southeast Alaska Regional Health Care Consortium; Standing Rock Sioux Tribe; Tohono O'odham Community Action; and United Indian Health Services.

To our teammates, with gratitude: Larry Alonso, FNP-BC, Native Diabetes Wellness Program; Carolee Dodge Francis, EdD, University of Nevada, Las Vegas; Itai Jeffries, PhD, Biwa Emergent Equity, LLC; Marjorie Santos, MPH, RN, Native Diabetes Wellness Program; and Chelsea Wesner, MPH, MSW, University of South Dakota.

The 17 Traditional Foods Project tribal partners were supported by the Division of Diabetes Translation, Centers for Disease Control and Prevention, and the Indian Health Service Special Diabetes Program for Indians, cooperative agreement CC-RFA-DP08-819 Using Traditional Foods and Ecological Approaches to Promote Health and Help Prevent Type 2 Diabetes in American Indian and Alaska Native Communities.

Dr Fullerton, Dr Dodge Francis, and Ms Wesner were supported by Intergovernmental Personnel Agreements funded by the Division of Diabetes Translation, Centers for Disease Control and Prevention. Dr Jeffries was supported by a sole source contract funded by the Division of Diabetes Translation, Centers for Disease Control and Prevention.

Ms Frank is now affiliated with the Pueblo of Isleta Behavioral Health Services, Albuquerque, New Mexico.

The findings and conclusions in this manuscript are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Author Information

Corresponding Author: Lemyra DeBruyn, PhD, Native Diabetes Wellness Program, Division of Diabetes Translation, Centers for Disease Control and Prevention, 1720 Louisiana Blvd NE, Albuquerque, NM 87110. Telephone: 505-270-1189. Email: Lemyra@q.com.

Author Affiliations: [1]Native Diabetes Wellness Program, Division of Diabetes Translation, Centers for Disease Control and Prevention, Albuquerque, New Mexico. [2]Department of Emergency Medicine, University of New Mexico Health Sciences

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Center, Albuquerque, New Mexico. [3]Native Diabetes Wellness Program, Division of Diabetes Translation, Centers for Disease Control and Prevention, Atlanta, Georgia.

References

1. Centers for Disease Control and Prevention. Diabetes report card 2017. 2018. https://www.cdc.gov/diabetes/pdfs/library/diabetesreportcard2017-508.pdf. Accessed January 1, 2020.
2. Diabetes Prevention Program Research Group. Long-term effects of lifestyle intervention or metformin on diabetes development and microvascular complications over 15-year follow-up: the Diabetes Prevention Program Outcomes Study. Lancet Diabetes Endocrinol 2015;3(11):866–75.
3. Dabelea D, Mayer-Davis EJ, Saydah S, Imperatore G, Linder B, Divers J, et al.; SEARCH for Diabetes in Youth Study. Prevalence of type 1 and type 2 diabetes among children and adolescents from 2001 to 2009. JAMA 2014;311(17):1778–86.
4. Dabelea D, Stafford JM, Mayer-Davis EJ, D'Agostino R Jr, Dolan L, Imperatore G, et al. Association of type 1 diabetes vs type 2 diabetes diagnosed during childhood and adolescence with complications during teenage years and young adulthood. JAMA 2017;317(8):825–35.
5. Centers for Disease Control and Prevention. National diabetes statistics report, 2017. 2017. https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf. Accessed January 1, 2020.
6. Hales CM, Carroll MD, Fryar CD, Ogden CL. Prevalence of obesity among adults and youth: United States, 2015–2016. NCHS Data Brief 2017;(288):1–8.
7. Bullock A, Sheff K, Moore K, Manson S. Obesity and overweight in American Indian and Alaska Native children, 2006–2015. Am J Public Health 2017;107(9):1502–7.
8. Popkin BM, Adair LS, Ng SW. Global nutrition transition and the pandemic of obesity in developing countries. Nutr Rev 2012;70(1):3–21.
9. Washburn WE, editor. History of Indian-white relations. Handbook of American Indians, vol 4. Washington (DC): Smithsonian Institution; 1988 .
10. Kunitz SJ. Disease and social diversity: the European impact on the health of non-Europeans. New York (NY): Oxford University Press; 1994.
11. Satterfield DW, Shield JE, Buckley J, Alive ST. So that the people may live (hecel lena oyate ki nipi kte): Lakota and Dakota elder women as reservoirs of life and keepers of knowledge about health protection and diabetes prevention. J Health Dispar Res Pract 2007;1(2):1–28.
12. Williamson DF, Thompson TJ, Anda RF, Dietz WH, Felitti V. Body weight and obesity in adults and self-reported abuse in childhood. Int J Obes Relat Metab Disord 2002;26(8):1075–82.
13. Satterfield D, DeBruyn L, Santos M, Alonso L, Frank M. Health promotion and diabetes prevention in American Indian and Alaska Native communities — Traditional Foods Project, 2008–2014. MMWR Suppl 2016;65(1):4–10.
14. Satterfield D, DeBruyn L, Francis C, Allen A. A stream is always giving life: communities reclaim native science and traditional ways to prevent diabetes and promote health. Am Indian Cult Res J 2014;38(1):157–90.
15. Stewart JE, Battersby SE, Lopez-De Fede A, Remington KC, Hardin JW, Mayfield-Smith K. Diabetes and the socioeconomic and built environment: geovisualization of disease prevalence and potential contextual associations using ring maps. Int J Health Geogr 2011;10(1):18.
16. Benoit SR, Hora I, Albright AL, Gregg EW. New directions in incidence and prevalence of diagnosed diabetes in the USA. BMJ Open Diabetes Res Care 2019;7(1):e000657.
17. Shonkoff JP, Garner AS; Committee on Psychosocial Aspects of Child and Family Health; Committee on Early Childhood, Adoption, and Dependent Care; Section on Developmental and Behavioral Pediatrics. The lifelong effects of early childhood adversity and toxic stress. Pediatrics 2012;129(1):e232–46.
18. Brockie TN, Heinzelmann M, Gill J. A framework to examine the role of epigenetics in health disparities among Native Americans. Nurs Res Pract 2013;2013:410395.
19. Brockie TN, Elm JHL, Walls ML. Examining protective and buffering associations between sociocultural factors and adverse childhood experiences among American Indian adults with type 2 diabetes: a quantitative, community-based participatory research approach. BMJ Open 2018; 8(9):e022265.
20. Felitti VJ, Anda RF, Nordenberg D, Williamson DF, Spitz AM, Edwards V, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. Am J Prev Med 1998;14(4):245–58.
21. Seligman HK, Bindman AB, Vittinghoff E, Kanaya AM, Kushel MB. Food insecurity is associated with diabetes mellitus: results from the National Health Examination and Nutrition Examination Survey (NHANES) 1999–2002. J Gen Intern Med 2007;22(7):1018–23.
22. Gordon A, Oddo V. Addressing child hunger and obesity in Indian Country: report to Congress. 2012. https://fns-prod.azureedge.net/sites/default/files/IndianCountry.pdf. Accessed January 1, 2020.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

23. Jernigan VBB, Huyser KR, Valdes J, Simonds VW. Food insecurity among American Indians and Alaska Natives: a national profile using the Current Population Survey–Food Security Supplement. J Hunger Environ Nutr 2017;12(1):1–10.
24. Blue Bird Jernigan V, Wetherill MS, Hearod J, Jacob T, Salvatore AL, Cannady T, et al. Food insecurity and chronic diseases among American Indians in rural Oklahoma: the THRIVE Study. Am J Public Health 2017;107(3):441–6.
25. Conti KM. Diabetes prevention in Indian country: developing nutrition models to tell the story of food-system change. J Transcult Nurs 2006;17(3):234–45.
26. Wesner C. Traditional foods in native America: a compendium of stories from the indigenous food sovereignty movement in American Indian and Alaska Native communities. Part I. Atlanta (GA): Native Diabetes Wellness Program, Centers for Disease Control and Prevention; 2013. https://www.cdc.gov/diabetes/ndwp/pdf/part-i---traditional-foods-in-native-america-april-21.pdf. Accessed January 3, 2020.
27. Wesner C. Part II. Good food is power: a collection of traditional foods stories from the Ramah Navajo Community, Standing Rock Sioux Tribe and Tohono O'odham Nation. Atlanta (GA): Native Diabetes Wellness Program, Centers for Disease Control and Prevention; 2014. https://www.cdc.gov/diabetes/ndwp/pdf/part-ii---good-food-is-power-april-21.pdf. Accessed January 3, 2020.
28. Wesner C. Traditional foods in native America — part III: a compendium of stories from the indigenous food sovereignty movement in American Indian and Alaska Native communities. Atlanta (GA): Native Diabetes Wellness Program, Centers for Disease Control and Prevention; 2015. https://www.cdc.gov/diabetes/ndwp/pdf/part-iii---compendium-of-traditional-foods-stories-june-9-508.pdf. Accessed January 3, 2020.
29. Wesner C. Traditional foods in native America — part IV: a compendium of stories from the indigenous food sovereignty movement in American Indian and Alaska Native communities. Atlanta (GA): Native Diabetes Wellness Program, Centers for Disease Control and Prevention; 2015. https://www.cdc.gov/diabetes/ndwp/pdf/Part_IV_Traditional_Foods_in_Native_America.pdf. Accessed January 3, 2020.
30. Wesner C. Traditional foods in native America — part V: a compendium of stories from the indigenous food sovereignty movement in American Indian and Alaska Native communities. Atlanta (GA): Native Diabetes Wellness Program, Centers for Disease Control and Prevention; 2018. https://www.cdc.gov/diabetes/ndwp/pdf/Part_V-Traditional_Foods_in_Native-_America_508tagged.pdf. Accessed January 3, 2020.
31. Jones L. A dam brings a flood of diabetes to three tribes. Indian Country Today. 2011Jul 6. https://newsmaven.io/indiancountrytoday/archive/a-dam-brings-a-flood-of-diabetes-to-three-tribes-UxirYly45ky80YsQ2v6EZw. Accessed December 2, 2019.
32. Joos SK. Economic, social, and cultural factors in the analysis of disease: dietary changes and diabetes mellitus among the Florida Seminole Indians. In: Brown LK, Mussell K, editors. Ethnic and regional foodways in the US: the performance of group identity. 4th edition. Knoxville (TN): University of Tennessee Press; 1984. p. 217–37.
33. Mihesuah DA, Hoover E, editors. Indigenous food sovereignty in the United States: restoring cultural knowledge, protecting environments, and regaining health. Norman (OK): University of Oklahoma Press; 2019.
34. Echo Hawk Consulting. Feeding ourselves: food access, health disparities, and the pathways to healthy Native American communities. Longmont (CO): Echo Hawk Consulting; 2015. https://nebula.wsimg.com/891e74d1afe847b92abe87b2a1df7c63?AccessKeyId=2EF8ECC329760AC5A98D&disposition=0&alloworigin=1. Accessed January 1, 2020.
35. Chino M, Haff DR, Dodge Francis C. Patterns of commodity food use among American Indians. Pimatisiwin: J Aboriginal and Indigenous Community Health 2009;7(2):279–89.
36. Nazarea VD. Ethnoecology as situated knowledge. In: Nazarea VD, editor. Ethnoecology: situated knowledge, located lives. Tucson (AZ): University of Arizona Press; 1999. p. 3–20.
37. Hunn ES. The value of subsistence for the future of the world. In: Nazarea VD, editor. Ethnoecology: situated knowledge, located lives. Tucson (AZ): University of Arizona Press; 1999. p. 23–36.
38. Moore K, Dodge-Francis C, DeBruyn L. American Indian Higher Education Consortium Honoring Our Health grant program. In: Liburd LC, editor. Diabetes and health disparities: community-based approaches for racial and ethnic populations. New York (NY): Springer; 2011. p. 257–74.
39. Chino M, Dodge-Francis C, DeBruyn L, Short L, Satterfield D. The convergence of science and culture: developing a framework for diabetes education in Tribal communities. J Health Dispar Res Pract 2007;1(3):75–87.
40. Wallerstein N, Duran B, Oetzel J, Minkler M, editors. Community-based participatory research for health: advancing social and health equity. 3rd edition. San Francisco (CA): Jossey-Bass; 2018.
41. Mariella P, Brown E, Carter M, Verri V. Tribally-driven participatory research: state of the practice and potential strategies for the future. J Health Dispar Res Pract 2009; 3(2):41–58.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

42. International Indian Treaty Council. An analysis of US international policy on indigenous people: the human right to food and food security. 2002. https://foodsecurecanada.org/sites/foodsecurecanada.org/files/Analysis_US_Policy_Indigenous_Right_to_Food.pdf. Accessed January 1, 2020.
43. NCAI Policy Research Center and MSU Center for Native Health Partnerships. 'Walk softly and listen carefully': building research relationships with Tribal communities. 2012. http://www.ncai.org/attachments/PolicyPaper_SpMCHTcjxRRjMEjDnPmesENPzjHTwhOlOWxlWOIWdSrykJuQggG_NCAI-WalkSoftly.pdf. Accessed January 1, 2020.
44. First Nations Development Institute. Food sovereignty assessment tool. 2nd edition. Longmont (CO): First Nations Development Institute; 2014. https://www.firstnations.org/publications/food-sovereignty-assessment-tool-2nd-edition/. Accessed January 1, 2020.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Tables

Table 1. Percentage of Grantee Partner Programs Engaging in Traditional Foods Project Activities by Period, Traditional Foods Project, October 2009–September 2014[a]

Activity	T1 (W) (n = 11)	T2 (S) (n = 11)	T3 (W) (n = 17)	T4 (S) (n = 17)	T5 (W) (n = 17)	T6 (S) (n = 17)	T7 (W) (n = 17)	T8 (S) (n = 17)	T9 (W) (n = 16)	T10 (S) (n = 16)	Median (T1–T10)
Planting and gardening activities	72.7	81.8	82.4	88.2	58.8	94.1	70.6	88.2	75.0	87.5	82.1
Community gardens	Not asked	54.6	41.2	52.9	41.2	64.7	52.9	64.7	37.5	50.0	51.4
Use of heirloom seeds	Not asked	Not asked	29.4	47.1	47.1	64.7	52.9	58.8	31.3	62.5	50.0
Composting	0	0	23.5	23.5	35.3	29.4	29.4	35.3	37.5	31.3	29.4
Healthy foods available in ≥1 venue	45.4	36.4	64.7	64.7	64.7	64.7	41.2	52.9	62.5	62.5	62.5
Health education activities/ materials	81.8	100.0	88.2	94.1	82.4	85.4	76.5	82.4	81.3	87.5	83.9
Media outreach activities	36.4	45.4	64.7	64.7	52.9	64.7	64.7	58.8	56.3	56.3	57.6
New health policies and practices	45.4	45.4	41.2	47.1	58.8	41.2	41.2	41.2	43.8	31.3	42.5
Collaborate with other agencies	100.0	90.9	94.1	94.1	100.0	94.1	94.1	100.0	100.0	87.5	94.1
Organized physical activities	72.7	72.7	64.7	82.4	52.9	64.7	35.3	70.6	50.0	50.0	64.7
Participant change measured	54.6	45.4	47.1	47.1	41.2	47.1	47.1	41.2	25.0	50.0	47.1

Abbreviations: S, summer; W, winter.

[a] The “n” in each column refers to the number of partners, which is the same as the number of programs.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

Table 2. Numbers of Stories and Participants, by Type of Media, Reported by All Traditional Foods Project Grantee Partners, Traditional Foods Project, October 2009–September 2014

Period	Narrative Stories		Digital Stories		Music, Plays, and Art Stories		Total	
	No. of Stories	No. of Participants	No. of Stories	No. of Participants	No. of Stories	No. of Participants	No. of Stories	No. of Participants
Time 1 (Winter)	73	787	14	47	19	740	106	1,574
Time 2 (Summer)	68	1,180	30	53	100	400	198	1,633
Time 3 (Winter)	155	1,088	132	68,416[a]	123	2,995	410	72,499
Time 4 (Summer)	193	1,495	34	109	136	1,668	363	3,272
Time 5 (Winter)	146	1,899	31	117	7	265	184	2,281
Time 6 (Summer)	82	1,319	24	141	37	498	143	1,958
Time 7 (Winter)	130	7,715	24	434	39	1,052	193	9,201
Time 8 (Summer)	101	1,717	18	94	113	771	232	2,582
Time 9 (Winter)	145	7,383	40	325	34	490	219	8,198
Time 10 (Summer)	112	10,975	55	142	108	899	275	12,016

[a] Includes the number of people reached through social media.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table 3. Themes and Theme-Specific Quotes From Traditional Foods Project Grantee Partners, Traditional Foods Project, October 2009–September 2014

Themes	Theme-Specific Quotes
Traditional knowledge and grassroots	• Focusing on traditions is where connections are made. • The focus on tradition and culture is the basis of this project. This is why it's so important at the grassroots. Otherwise it is "just funding with a Native design." • Traditional ecological knowledge guides the way in balance with western science. • Top-down models don't work well. What works is "on the ground." • Our elders get this. • What we've done here is show that tribes can do what works for them. • It is brave to define truth; what tribes know is important. • Traditional foods are probably one of the most important elements in any Native American/Alaskan Native's culture. • This project is not a temporary spark for this community, but a lifestyle deeply rooted in our culture. We must continue this effort to eat healthily and keep moving. We must all lend a hand and be part of a voice in keeping our people healthy. • Being on the land allows for learning more deeply through host grantee's history, culture, and traditions that shape their food system. • No matter how we design our data collection instruments, only members of our communities can make true assessments of the impacts and outcomes of an intervention. • Participation in the sacred may not be a requirement of a federal job, but is almost always a requirement of working effectively with tribes.
Connections to health	• We are reconnecting land and water with health. • Traditional foods have become the way to talk about health. • Traditional foods provide an alternative to high-cost, low-quality foods offered in many tribal communities by convenience and grocery stores. • Type 2 diabetes is part of intergenerational trauma. • Diabetes and related diseases have been with our communities for 1 or 2 generations, and in many cases, traditional foodways that can prevent, treat, and cure these diseases have been gone for that amount of time or longer. It's going to take at least that long to meaningfully address these diseases.
The power of stories and storytelling	• Such great stories are told through presentations about changing a person's life or what an elder said. Can we capture these compelling moments? The reporting we do is so rich with stories. • At the time we incorporated the Eagle Books to our program, what helped was how relatable the books were to our kids. When the lessons were in story form, the students stayed interested in the health messages we were trying to get across. • Each traditional food procurement involves not only the return to a healthier subsistence diet but the physical activity associated with growing or obtaining the food. It also requires a sharing of stories and knowledge about how it is prepared or how that food shaped the lives of the ancestors. Such stories span generations.
Community engagement	• Youth are being engaged in learning traditional knowledge and helping their people. • This project has community members working together who wouldn't ordinarily have the opportunity. • It took 3 years for our tribe to gain full community buy in. Volunteers are abundant resources now. • Tribal members are participating in Traditional Foods advisory boards and food policy councils. • Traditional foods projects are supporting traditional knowledge. • We envision these garden spaces to be more than just a place to grow food, but also a place where community members can gather. • Our community sees the change this program has made — this is extraordinary for our people who are so often hopeless that they can change their situation. Not only that, they stood as witnesses to the successes felt in the larger community of TF partner sites. • It is exciting that traditional foods are resonating with youth. These spaces for intergenerational community are ever-valuable in a modern world where young people communicate mostly through digital mediums.
Knowledge sharing and gratitude	• Food is good medicine. Traditional foodways include responsibility, giving thanks, and sharing. • Sharing traditional foods and cultural practices is the foundation of our program. • We got this idea from [name of TFP partner]. Sharing across the country and across the room is meaningful and helpful. • The emergence of the theme of how spiritual our traditional foods are — the big picture. I think we all have known this, but it was amazing to me that this emerged at a meeting and flowed freely. This was a refreshing time for me. • My great aunt used to tell me that our foods taste better when we share them. In this case [TFP meeting] we shared them with our own local Native community and with all of the other communities represented. The good feelings were palpable and dinner was delicious. • It is great to expand to Indian Country and share what we have learned. • Thank you for giving me one of my life's biggest blessings — the chance to be part of this group. I ask the Creator to bring us all together again. • I feel like part of a large family of inspiration and affirmation.
Flexibility to do what works	• The flexibility to do what works is invaluable. In our experience with federal programs, we are not doing what you want us to do most of the time. With this program, we are doing exactly what you want us to do! • Policy seems most effective if it comes from the grassroots. Policy, or practice, that allows people to have choice is bridged with traditional practice. • Practice-based evidence is what we are doing. • There are impacts the TFP is not measuring like substance abuse and environmental health. • We are recognizing tribal sovereignty. • Do I really get to do this?
Program sustainability	• It took a long time for our people to get sick. Sustainability will not happen in 4 to 5 years. • It would be a shame not to continue these programs without giving them a chance to show the impact of this work. • Just imagine what we could do with another cycle! We have shared and borrowed so much from each other already. We could deepen this effort. • The Traditional Foods Project has made an impact on this reservation. Maybe a decade or two ago there were only a handful of gardens here. Now we till over 50. That is equivalent to almost one-fourth of the households raising their own garden.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 18, E07 JANUARY 2021

PROGRAM EVALUATION BRIEF

Pharmacist Involvement in Addressing Public Health Priorities and Community Needs: The Allegheny County Racial and Ethnic Approaches to Community Health (REACH) Project

Jennifer Padden Elliott, PharmD[1]; Stephanie N. Christian, MPH[2]; Katie Doong, PharmD[3]; Hannah E. Hardy, MPA[4]; Dara D. Mendez, PhD, MPH[5]; Tiffany L. Gary-Webb, PhD, MHS[5]

Accessible Version: www.cdc.gov/pcd/issues/2021/20_0490.htm

Suggested citation for this article: Elliott JP, Christian SN, Doong K, Hardy HE, Mendez DD, Gary-Webb TL. Pharmacist Involvement in Addressing Public Health Priorities and Community Needs: The Allegheny County Racial and Ethnic Approaches to Community Health (REACH) Project. Prev Chronic Dis 2021;18:200490. DOI: https://doi.org/10.5888/pcd18.200490.

PEER REVIEWED

Summary

What is already known on this topic?

The Centers for Disease Control and Prevention published a framework for community pharmacists and physicians to promote community–clinical linkages; most successful models function within traditional health care settings.

What is added by this report?

Given multiple barriers to accessing health care in African American and underresourced urban communities, a community-based pharmacist navigation program delivers clinical preventive services including screening, behavioral counseling, and referral to clinical, social, or behavior-change programs, in nontraditional health care settings.

What are the implications for public health practice?

With the inclusion of pharmacists in existing payment models, this community-based pharmacist navigation program model can be readily adapted and implemented by other community-based pharmacists and have a major public health impact.

Abstract

Community–clinical linkages are connections between community and clinical sectors to improve population health, and community-based pharmacists are well positioned to implement this strategy. We implemented a novel approach to community–clinical linkages in African American communities in which community-based pharmacists implement screenings for chronic disease and social determinants of health, make referrals to clinical and social services, and follow up with patients to support linkage to care in nontraditional health care settings. The community-based pharmacist navigation program works with multisector partners to increase referrals and access to existing health and social service programs. We used a mixed-methods evaluation approach to collect and analyze data on program characteristics and the linkage intervention. From February 2019 to March 2020, 702 African American community members received preventive health screenings, and 508 (72%) were referred to clinical and social services. Pharmacists demonstrated the ability to implement clinical preventive services in nontraditional health care settings and improve access to care through the provision of community–clinical linkages.

Introduction

Despite national progress and a narrowing of health gaps by race and ethnicity for some health outcomes, substantial racial and ethnic disparities in health persist for chronic diseases such as diabetes and heart disease (1). In the United States, heart disease is the leading cause of death among African American people, who are 20% more likely than White people to die of a myocardial infarction (2). These trends are similar in Allegheny County, Pennsylvania, the 34th largest county in the United States, with more than 1.2 million people residing in 130 municipalities, including Pittsburgh (3–5). African American people comprise approximately 13% of the population of Allegheny County, yet many communities, especially several in Pittsburgh and others along the rivers, are racially segregated, producing census tracts with a predominately African American population and high

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

poverty rates. Chronic disease rates in the county do not differ significantly from those of the state or nation; however, in census tracts comprising a predominately African American population, rates of chronic disease prevalence are high, driven by health inequities (3).

In 2018, the Allegheny County Health Department received a cooperative agreement from the Centers for Disease Control and Prevention (CDC) as part of its Racial and Ethnic Approaches to Community Health Program (REACH) to implement the Live Well Allegheny: Lifting Wellness for African Americans (LWA^2) project and work in 6 priority communities in the county to reduce racial health disparities. The LWA^2 project was developed in response to the most recent community health assessment and a review of community-level data; its leadership includes a diverse coalition of more than 25 partners working together to improve nutrition, breastfeeding support, physical activity, and community–clinical linkages (CCLs) for African Americans living in selected communities (www.livewellallegheny.com/reach). LWA^2 partners work across sectors and have strong ties with their communities. Although individual behavior changes can improve personal and community health outcomes, system changes are also needed to achieve equity and ensure that residents live well, no matter their zip code or race. Therefore, the coalition advocates for policies that increase access to health care, hospitals, grocery stores, farmers markets, and transportation. The 5-year initiative (2018–2023) bridges the gap between government, schools, churches, nonprofit organizations, and community members of all ages. The goal of the project is the creation of a city where African Americans achieve optimal health and live well.

CDC supports the development of CCLs, which are connections between the community and health care clinics and among other settings where primary care is provided to improve population health (6). Community-based pharmacists practice in settings where patient care is delivered outside the inpatient health system, and they have demonstrated the ability to implement patient care services such as comprehensive medication management, point-of-care testing, and immunization delivery to address various public health concerns (7–9). The Association of American Medical Colleges projects that the demand for primary care providers will continue to exceed the supply (10). As demand for primary care services continues to increase, community-based pharmacists are in a unique position to help fill this health care gap by providing accessible preventive care and CCLs. CDC published a framework for community pharmacists and physicians to promote CCLs; most successful models function within traditional health care settings (11). The physical location of community pharmacies helps improve access to care. More than 90% of the US population lives within 5 miles of a community pharmacy; however, barriers to access to traditional health care settings still exist (12). Given multiple barriers to accessing health care in African American and underresourced urban communities, the Live Well Allegheny REACH Coalition implemented a community-based pharmacist navigation program to deliver clinical preventive services, including screening, behavioral counseling, and referral to clinical, social, or behavior-change programs, in nontraditional health care settings.

Purpose and Objective

The objective of our study was to describe an evaluation of our novel approach to CCLs. We used a community-based pharmacist navigation program to screen community members for chronic disease and social determinants of health, make referrals to clinical and social services, and follow-up to support the linkage to care in nontraditional health care settings (Figure). Evaluation methods are aligned with the CCL framework from the Agency for Healthcare Research and Quality and focus on program characteristics and the linkage intervention (13). We evaluated short-term outcomes, including number and types of screenings, referrals, and uptake, for February 2019 through March 2020.

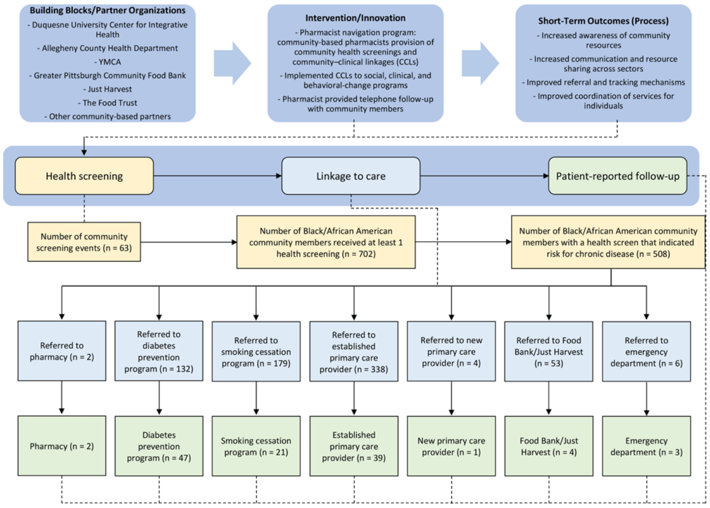


Figure. Description of the project, referrals to community resources, and follow-up in a community-based pharmacist navigation program implemented in predominately African American communities, Allegheny County, Pennsylvania, 2019–2020.

Intervention Approach

Community-based pharmacists practicing in the Duquesne University Center for Integrative Health's Community Care Clinic implemented the pharmacist navigation program in 6 REACH priority communities. During the planning phase (October 2018–Febru-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

ary 2019) Duquesne's community-based pharmacists worked with the ACHD, federally qualified health centers, community pharmacies, local providers of behavior-change programs (National Diabetes Prevention Program [NDPP], smoking cessation programs), and local food assistance programs to create maps of neighborhood assets. Maps are made available as hard copies and electronically and are updated monthly with current information about programs in each neighborhood. The maps were designed to be easy to read and to accompany all referrals to clinical or social services.

A community-based screening program was designed to include pop-up point-of-care testing for hypertension, diabetes, high cholesterol, and cigarette smoking — all major risk factors for heart disease — and food insecurity screening, counseling, and referral to community services. The Duquesne Community Care Clinic has a Clinical Laboratory Improvement Amendments (CLIA) Certificate of Waiver that allows their community-based pharmacists to perform CLIA-waived point-of-care tests. All health screenings are free to community members and provided by pharmacists, pharmacy practice residents, and student pharmacists, under the supervision of a licensed pharmacist. Pharmacists, pharmacy practice residents, and student pharmacists undergo standardized training on point-of-care testing before providing preventive health screenings at community-based screening events. Pharmacists work with multisector partners to plan health screenings at large community events (festivals, back-to-school events, food drives) as well as regularly scheduled screenings in high-traffic locations in each neighborhood (grocery stores, farmers markets, senior living centers, food distribution sites, YMCAs). Regularly scheduled screenings take place at the same time and location each month to increase access to initial and follow-up health screenings.

Residents aged 18 years or older are eligible to participate in the program. Participants whose screening test indicates chronic disease, chronic disease risk, or food insecurity receive counseling and education from a pharmacist and are referred to one or more of the following: an emergency department for critical values, an established primary care provider, a new primary care provider (if appropriate), a behavior-change program (NDPP, smoking cessation program), a community pharmacy that offers enhanced services, or a food assistance program to help with immediate (food pantries) or long-term needs (enrollment in the Supplemental Nutrition Assistance Program). After the screening event, a pharmacist or pharmacy-practice resident follows up twice via telephone with each participant whose screening test indicated at least 1 chronic disease, chronic disease risk, or food insecurity. The first follow-up call is scheduled 1 or 2 weeks after the initial referral to provide additional counseling, identify any barriers to the referral, and to support linkage to care. The second follow-up call is scheduled 1 or 2 months after the initial referral to evaluate linkage to the referral agency and any additional barriers that can be communicated to multisector partners.

Evaluation Methods

To evaluate the progress of the activities executed by the community-based pharmacist navigation program and other partners in the REACH coalition, the evaluation team used a mixed-methods approach to collect and analyze data. Monthly coalition meetings, annual data collection on performance measures, key informant in-depth interviews, and focus groups are ongoing. In addition to providing the coalition with necessary updates from funders and the ACHD, monthly coalition meetings allow partners to provide the larger group with updates on their progress and open the discussion for relevant collaborations. Each year, partners provide the evaluation team with performance measures and metrics. For the community-based pharmacist navigation program, Duquesne University Center for Integrative Health reports deidentified data extracted from the Community Care Clinic's electronic health record system for screening events that took place in priority neighborhoods from February 2019 through March 2020. These data included the number of screening events and locations; where people were referred; the number of people screened; the demographic characteristics of people screened; the types of screening performed; the number of screenings that indicated at least 1 chronic disease, 1 chronic disease risk factor, or food insecurity; and the number of people that self-reported enrollment in applicable programs as a result of the referrals. Screening data were collected at each event and enrollment data were collected during the follow-up process.

REACH coalition leadership had conducted semistructured interviews in person with partner organizations from January 2020 through May 2020 to gather information about the development and progress of coalition activities and availability of community-based resources. The results of the interviews provide insight to better inform and improve coalition strategies. The interviews included questions about each partner organization and its relationship to REACH, its process for planning and development, implementation processes, community relationships, relationships with the larger coalition, challenges and successes, and recommendations for continuing activities. The interviews were audio recorded, transcribed, and later coded by 2 researchers using NVivo qualitative software version 12 (QSR International). After submission to the evaluation team, all data are reviewed, analyzed, and submitted to CDC.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Results

Preventive health screenings and linkages to care were provided at 63 events in Allegheny County from February 2019 through March 2020. A total of 702 community members who identified as Black or African American received at least 1 health screening, and 508 community members were referred to 1 or more clinical or social services (Figure).

The qualitative analysis of the semistructured interviews revealed 4 dominant themes of the implementation, planning, and development process of the pharmacist navigation program: methods for choosing neighborhood screening events, screening implementation, planning and development of the referral system, and methods for conducting follow-up (Table). During the first year, partners chose to work in neighborhoods that were most familiar to them or those in which they had physical locations. Pharmacists played an essential role in implementing and executing the regularly scheduled health and social determinants of health screenings. The network of REACH partners and community-based organizations constituted accessible referral organizations. Additionally, follow-up calls were conducted methodologically to further support the CCL.

Implications for Public Health

The community-based pharmacist navigation program implemented in Allegheny County highlights the impact of community-based pharmacists on providing preventive health services and care coordination in nontraditional health care settings in neighborhoods at risk of poor health outcomes. Through the implementation of this model, pharmacists partnered with trusted community-based programs and delivered services in locations frequently visited by residents. This CCL model allows community-based pharmacists to extend their reach outside traditional health care walls to meet community members where they are and decrease barriers to clinical and social services. The effect of the community-based pharmacist navigation program aligns with the effect described in previous studies of pharmacist-provided preventive health screenings and care coordination in traditional and nontraditional health care settings (14,15). The number of community members reached through our program was similar to the numbers described in other work; however, our focus on CCL and the integration of the multisector REACH partners into the referral process was unique. Our model can be easily expanded or modified to include other clinical and social services. Substance use disorder screenings have been added to our model, along with naloxone distribution and connection to medication-assisted treatment programs. Our model also offers the potential to implement other social determinants of health screenings in addition to food insecurity, as long as systems are in place and partners can provide the resources needed.

We faced challenges in documenting patient-reported follow-up with clinical and social services. Some residents did not answer telephone calls and some telephone numbers were disconnected. Additionally, pharmacists initially made both follow-up telephone calls within 2 weeks of the screening event. We quickly determined that although this time frame supported linkage to care, it did not give residents enough time to connect with the referral, and, thus, the short time frame negatively affected accurate documentation of linkage to care. The second follow-up telephone call was changed to 1 or 2 months after the screening event, which improved documentation of linkage to care. This time frame also allowed pharmacists to collect information on remaining barriers that could be shared with the REACH coalition and other multisector partners. As an additional strategy to improve linkages to care and documentation, we implemented data-sharing agreements with local food assistance programs and are currently working on similar agreements with federally qualified health centers.

The process of creating the community asset maps showed few behavior-change programs available to residents in some REACH communities. Additionally, follow-up telephone calls showed that some programs had inconvenient hours and locations. The REACH coalition has since created several virtual chronic disease management and support programs, such as the NDPP, smoking cessation programs, and comprehensive medication management. The opportunity also exists to support community-based pharmacists to implement NDPP in their practice sites, especially in community pharmacies.

Community-based pharmacists can substantially improve access to care through implementation of CCLs in both traditional and nontraditional health care settings. However, reimbursement opportunities are limited for community-based pharmacists to provide enhanced patient care services, such as point-of-care testing. Payment models will need to be developed to ensure community-based pharmacists can continue to develop, grow, and provide patient care services to improve access to care, help fill the need for primary care services, and connect historically hard-to-reach patient populations to resources in traditional and nontraditional health care settings. With the inclusion of pharmacists in existing payment models, this community-based pharmacist navigation program model can be readily adapted and implemented by other community-based pharmacists and have a major public health impact.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Acknowledgments

The authors have no financial conflicts of interest relevant to this article. Our work was funded by the CDC's REACH program. We thank the REACH funders, partners, community ambassadors and participants for making this work possible. No copyrighted materials or tools were used in this article.

Author Information

Corresponding Author: Jennifer Elliott, PharmD, Director, Center for Integrative Health, Associate Professor, School of Pharmacy, Duquesne University, 308 Bayer Learning Center, 600 Forbes Ave, Pittsburgh, PA 15282. Telephone: 412-396-4990. Email: elliott3@duq.edu.

Author Affiliations: [1]Duquesne University, Center for Integrative Health, School of Pharmacy, Pittsburgh, Pennsylvania. [2]University of Pittsburgh Graduate School of Public Health, Department of Behavioral and Community Health Sciences, Pittsburgh, Pennsylvania. [3]Giant Eagle Pharmacy, Pittsburgh, Pennsylvania. [4]Allegheny County Health Department, Chronic Disease and Injury Prevention Program, Pittsburgh, Pennsylvania. [5]University of Pittsburgh Graduate School of Public Health, Department of Epidemiology, Pittsburgh, Pennsylvania.

References

1. National Center for Health Statistics. Health, United States, 2015: with special feature on racial and ethnic health disparities. Report no. 2016-1232. Hyattsville (MD): National Center for Health Statistics; 2016.
2. US Department of Health and Human Services, Office of Minority Health. Heart disease and African Americans. https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=19. Accessed August 9, 2020.
3. Devaraj S, Stewart A, Baumann S, Elias TI, Hershey TB, Barinas-Mitchell E, et al. Changes over time in disparities in health behaviors and outcomes by race in Allegheny County: 2009 to 2015. J Racial Ethn Health Disparities 2020; 7(5):838–43.
4. Selker K. Allegheny County mortality report: 2016. Pittsburgh (PA): Allegheny County Health Department, Bureau of Assessment, Statistics and Epidemiology; 2018.
5. Howell J, Goodkind S, Jacobs LA, Branson D, Miller L. Pittsburgh's inequality across gender and race 2019. https://www.ywcapgh.org/wp-content/uploads/sites/97/Pittsburgh-GEC-Inequities-Across-Race-and-Gender-Sept-2019.pdf. Accessed August 9, 2020.
6. Centers for Disease Control and Prevention. Community-clinical linkages for the prevention and control of chronic diseases: a practitioner's guide. https://www.cdc.gov/dhdsp/pubs/docs/ccl-practitioners-guide.pdf. Accessed August 9, 2020.
7. Bluml BM, Watson LL, Skelton JB, Manolakis PG, Brock KA. Improving outcomes for diverse populations disproportionately affected by diabetes: final results of Project IMPACT: Diabetes. J Am Pharm Assoc (2003) 2014;54(5):477–85.
8. Isho NY, Kachlic MD, Marcelo JC, Martin MT. Pharmacist-initiated hepatitis C virus screening in a community pharmacy to increase awareness and link to care at the medical center. J Am Pharm Assoc (2003) 2017;57(3S3s):S259–64.
9. Drozd EM, Miller L, Johnsrud M. Impact of pharmacist immunization authority on seasonal influenza immunization rates across states. Clin Ther 2017;39(8):1563–1580.e17.
10. Association of American Medical Colleges. The complexities of physician supply and demand: projections from 2018 to 2033. 2020. https://www.aamc.org/system/files/2020-06/stratcomm-aamc-physician-workforce-projections-june-2020.pdf. Accessed August 9, 2020.
11. Centers for Disease Control and Prevention. Creating community–clinical linkages between community pharmacists and physicians. https://www.cdc.gov/dhdsp/pubs/docs/ccl-pharmacy-guide.pdf. Accessed August 9, 2020.
12. Qato DM, Zenk S, Wilder J, Harrington R, Gaskin D, Alexander GC. The availability of pharmacies in the United States: 2007–2015. PLoS One 2017;12(8):e0183172.
13. Porterfield DS, Hinnant LW, Kane H, Horne J, McAleer K, Roussel A. Linkages between clinical practices and community organizations for prevention: a literature review and environmental scan. Am J Public Health 2012;102(Suppl 3):S375–82.
14. Stratton TP, Williams RG, Meine KL. Developing a mobile pharmacist-conducted wellness clinic for rural Montana communities. J Am Pharm Assoc (2003) 2005;45(3):390–9.
15. Palombi LC, Bastianelli K, Stratton T. Point-of-care screenings at the University of Minnesota: mechanism for civic engagement. J Am Pharm Assoc (2003) 2014;54(1):56–62.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table

Table. Supporting Quotes From Qualitative Interviews on the Implementation, Planning, and Development Process of the Community-Based Pharmacist Navigation and Referral Program

Theme and Findings	Quote
Methods for choosing neighborhood screening events	
• Neighborhood choice and frequency of screenings were decided by partners during the first year • Partners decided to work with familiar communities first	There wasn't always consistency in what health screening was offered, and the locations varied. So part of the planning through REACH [Racial and Ethnic Approaches to Community Health], when we looked at the priority neighborhoods . . . our efforts would be diluted if we tried to start working in all 22 neighborhoods at one time. So we thought, let's start in the neighborhoods where one of us or a few of us already have relationships and have a presence and develop something together that can then be replicated to other neighborhoods.
	For year one, we chose the Hill District. We had the pharmacy in the Hill for some time, and we still have it. We chose Clairton because a lot of my work has been in Clairton. And we chose Homewood, and that was the Y[MCA] wanted to start in Homewood. And we felt that was good for us because we had 2 sort-of established neighborhoods and a new neighborhood. So that was sort of the process, and it took us probably that first — it wasn't a full year, but it was kind of like a half a year that first planning year.
	[D]oing regular screenings is also new. So we would do them at different events that people would request. And we had some sites that were regular. But now, we're being very intentional that we're there monthly so that people can say, "If you want a free blood glucose test or a free cholesterol, go to here on this day. They're here every second Tuesday of the month."
	So our population base really comes from 3 locations. . . . Those are our 3 demographic zip codes that we have chosen to really attack first, mainly because we have branches and sites there that we're able to work out of. So a lot of our screening opportunities come from there. And we have a good relationship with those communities. . . . We want to make sure that we're doing right by communities that we're working in right now. We want to make sure that those efforts are really done to our fullest before we move on. And I think the greatest part about our opportunity here is that we do not have to work inside of our 4 walls. This program is really movable in and throughout the community.
Screening implementation	
• Duquesne's staff played an essential role in conducting screenings and recording data • Screenings were regularly scheduled • Various vitals were taken at the screenings, including the addition of food insecurity screening	So there's the student pharmacist involvement and the screenings. And then we also do the Hunger Vital Sign screening, which was not part of what we did before, and that happened because of REACH because we're all brought together and introduced to this.
	We had the intention to do these regular screenings, but it took a while for that to happen, to set up where it was going to be, and whatnot. So it was a lot of maybe the existing relationships that we had and kind of deciding on best partners and times.
	We have really greatly increased the number of health screenings that we're doing due to wanting to have that presence in our neighborhoods. And because of that, we also had to think of creative ways to be able to do that many health screenings.
	We have monthly screenings. . . . And it is us with the Duquesne pharmacy too, doing blood pressures, CO [carbon monoxide] screenings, and testing glucose screenings. They're going to do cholesterol every other month. And this is open to the community. Members and nonmembers alike are able to come in.
	Duquesne was willing to step up and say, "Hey, we have the student power. We have 70-plus people that are going to be here. Let us take care of the Excel sheets and bring the data. And, oh, we can do these types of screenings and you can do this. And you put a program here, and we're going to put one here." And The Food Trust came and said, "Hey, if there's individuals that are coming that are hungry, let us give you a food box." . . . What a great partnership we had.
	I would say that 95% of all screenings that we do are in partnership with them [Duquesne]. So the ability for those data points to be usable across both spectrums is huge because them having a dedicated 10-student team to create these intricate Excel sheets . . . is huge.
	[W]e had worked with Duquesne to actually implement a food insecurity screening question as part of their full assessment that they were doing.
Planning and development of the referral system	
• The network of REACH partners and relationships with community-based organizations created opportunities for referrals • Resource accessibility was considered when referrals were made to residents	[W]e created a map of the existing resources in each neighborhood, and we continue to update that as things change and as we learn of new resources.
	[W]e have relationships with the various FQHCs [federally qualified health centers] and providers in those neighborhoods. So we also had been doing the work and knowing that sometimes we were the first person

(continued on next page)

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

(continued)

Table. Supporting Quotes From Qualitative Interviews on the Implementation, Planning, and Development Process of the Community-Based Pharmacist Navigation and Referral Program

Theme and Findings	Quote
• Referrals were made in real time at the screening events	that checked this person's blood pressure in 10 years and so that we had the ability to identify them and connect them to some of these existing resources. So I think that the maps, we knew, were something that we needed to do first and that we would continually update them as we learned some of these newer neighborhoods.
	[W]e now have the ability for anyone that comes to see us at these screenings to reference any of our partners. If they are there for blood pressure, glucose, CO screenings, if they have questions about their medication, pharmacy, mental health, not seeing a doctor, they can refer them onto a doctor. Food, insecurities, any of those needs, we can reference and get them down. If they have problems at home, not being able to pay their bill, the furnace is down, or air conditioner is down, we can refer them . . . to see if they can get help there. So kind of moving from the first screening we've ever had to a place where we're there to do blood pressure to, now, being able to serve the community.
	We are now spending more time on the marketing, on the focus, on the screenings in these areas where we were, but in the back of our minds, we also knew that this was not an affordable program for someone. And we're essentially going to do screenings and tell them about a program that they weren't going to be able to take because the Y could not give it out for free. We did not have grant dollars. But now that we know that we can provide this service, it's a much bigger focus.
	[S]o then we decided like, "Hey, we know Duquesne is going to be here. How about we email them and see if I can partner with them. People go through their screening, after them, you'll come talk to me, and I'll give you the Food Bucks."
	[O]ne of the ways that we've gotten referrals, particularly for SNAP [Supplemental Nutrition Assistance Program], is for individuals who are screening positive at those health screenings and then need connection to the SNAP team.
	So we're currently working on a direct referral to . . . a navigator for our programs. So they would work with that individual to connect them to any and all of our programs if they needed it besides SNAP. So that was not something that we went into REACH expecting but it's been a really great partnership. And Duquesne is doing the screenings at Produce to People. And we've just also started some conversation about having them do screenings at a few of what we call our Healthy Pantries. So that's been exciting and not something that was intended but has allowed us to expand our reach through some of the work that we're doing with health care providers with Duquesne Pharmacy.
Methods for conducting follow-ups with referrals	
• Follow-ups with residents were done in a methodological manner • Follow-ups were used to ensure that residents received care by working with them to guarantee access to services	I think this work gave us the capacity to come together with other partnering organizations to say, "We can do this, and we've been doing this. But how can we take it to the next level?" And knowing that these are high-risk patients that might have many reasons why they're not going to be able to enroll in such and such a program, how can we come together and make it easier? So I think that was the thought behind these follow-ups being very intentional of helping.
	[W]e'll call 1 time within a week to 2 after the event. And that serves as that kind of extra connection of, "Do you have that referral? What do you think of . . ." and then a month to 2 later for us to say, "Were you able to make it?" and, "Why not?" And only do 2 each time, and if they don't pick up, we're just not going to have that data. So that's where we are, and we are open to anyone's suggestions. But that was definitely something that we learned and adjusted.
	Another part that is new that I'm really excited about is we will do these screenings, and we would say, "Your blood sugar is 400. You need to go to your doctor." We will call on critical values. So anyone who had a critical value, we would call them 3 times in the next week until we got a hold of them to make sure that they were connected to care. But for the other patients, we weren't always doing that consistent follow-up. And so now because of REACH and it being part of it is we're calling everyone who's received a health screening and seeing . . . doing the same thing for those critical values, but calling everyone, and calling further out to see, "Did you go to that diabetes prevention program? Did you sign up for SNAP? Did you . . .?" not to make them feel judged if they didn't, but to say so that we can learn how to better serve the residents, "Why did you go to Hazelwood Health Center?," but, "Why didn't you sign up for this?" And then we're going to try to just keep track of the comments so we can learn what barriers might exist. And we didn't do that before.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 20, E67 AUGUST 2023

IMPLEMENTATION EVALUATION

A Communitywide Collaboration to Increase Enrollment, Retention, and Success in Evidence-Based Lifestyle-Change Programs in Racial and Ethnic Minority Populations

Maura Kepper, PhD[1]; Katherine A. Stamatakis, PhD[2]; Natalie Mudd, MSW[1]; Ariel Deitch[1]; Ally Terhaar, MPH[2]; Julia Liu, MPH[1]; Emerald Gates, MPH[3]; Bobie Williams, MS[4]; Gabrielle Cole, MNM[5]; Carolyn S. French, DTR[6]; Amy Hampton[7]; Amy Eyler, PhD[1]

Accessible Version: www.cdc.gov/pcd/issues/2023/22_0352.htm

Suggested citation for this article: Kepper M, Stamatakis KA, Mudd N, Deitch A, Terhaar A, Liu J, et al. A Communitywide Collaboration to Increase Enrollment, Retention, and Success in Evidence-Based Lifestyle-Change Programs in Racial and Ethnic Minority Populations. Prev Chronic Dis 2023;20:220352. DOI: https://doi.org/10.5888/pcd20.220352.

PEER REVIEWED

Summary

What is already known on this topic?

Evidence-based lifestyle-change programs can reduce the burden of chronic disease. Unmet social needs disproportionately affect Black populations and the ability to enroll in and complete lifestyle-change programs.

What is added by this report?

We describe an example of how health care, public health, and community partners can work together to increase recruitment, enrollment, and success of Black people in evidence-based lifestyle-change programs.

What are the implications for public health practice?

Lessons learned from implementation and evaluation of lifestyle-change programs may be applied to other complex partnerships between clinical and community-based organizations to improve the health and well-being of people who are disproportionately affected by chronic disease.

Abstract

Purpose and Objectives

Chronic diseases (eg, diabetes, hypertension) are the leading causes of death in the US and disproportionally affect racial and ethnic minority populations. This disparity is partially due to the unequal burden of unmet social needs that stem from several factors, including racism.

Intervention Approach

The Alliance is a collaboration among health care, public health, and community organizations formed to improve referral, enrollment, and successful completion of evidence-based lifestyle-change programs, particularly among Black people. The Alliance built 1) a system to assess and address social barriers through the screening and referral process and 2) a training center for frontline staff (eg, community health workers).

Evaluation Methods

From January 2020 through September 2022, we conducted an evaluation that included both quantitative and qualitative methods. We developed an electronic database to make referrals and track key barriers to participation. Additionally, we conducted a focus group among frontline staff (N = 15) to understand the challenges in making referrals and discussing, documenting, and addressing barriers to participation. We used surveys that collected quantitative and open-ended qualitative responses to evaluate the training center and to understand perceptions of training modules as well as the skills gained.

Results

Frontline staff engaged with 6,036 people, of whom 847 (14%) were referred to a lifestyle-change program from January 2020 through September 2022. Of those referred, 257 (30%) were eligible and enrolled in a program. Food access and unreliable internet were the most common barriers to participation. Thirteen of 15 frontline staff participated in trainings, and, on average, trainees completed 4.2 trainings and gained several skills (eg, ability to

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

This publication is in the public domain and is therefore without copyright. All text from this work may be reprinted freely. Use of these materials should be properly cited.

monitor personal bias, de-escalate a crisis, educate on mental health, understand community and environmental factors).

Implications for Public Health

The Alliance is an example of how health care, public health, and community partners can work together to increase enrollment in lifestyle-change programs of residents disproportionately affected by chronic diseases. Lessons learned from implementation and evaluation can inform other complex partnerships to improve public health.

Introduction

Chronic diseases such as diabetes, heart disease, hypertension, and stroke are the leading causes of illness, disability, and death in the US (1). Approximately half of the US population has a chronic disease, and these diseases account for 86% of all health care costs (2,3). More than 133 million Americans have diabetes (37.3 million) or prediabetes (96 million) (4). Diabetes and other chronic diseases disproportionally affect racial and ethnic minority groups. In 2018 in St. Louis City, the disparate burden of diabetes offered a stark example: the prevalence of diabetes was 13.4% among Black residents and 5.5% among non-Hispanic White residents, while diabetes mortality was 26.8 per 100,000 Black residents and 21.0 per 100,000 non-Hispanic White residents (5). Chronic diseases are affected by interdependent genetic, social, economic, cultural, and historical factors (6). The unequal burden of unmet social needs among Black people also contributes to chronic disease disparities (4,7).

The disparity in unmet social needs among Black people stems from racism, the unjust social, economic, and political oppression of non-Hispanic White people in the US. Racism occurs at multiple levels, including systemic racism, which creates structural barriers to health care access, and interpersonal racism, enacted by health care providers on their patients (7,8). Unmet social needs not only affect the risk of developing a chronic disease but also contribute to a disproportionate level of complications among non-Hispanic Black people (9,10). Despite the higher prevalence of chronic diseases and complications among Black people, they are less likely to receive recommended preventive care (9,11). The work described here focuses on addressing interpersonal racism, by training frontline staff who provide care for Black people, and structural racism, by providing resources to address unmet social needs that stem from inequitable environments and systems.

The Centers for Disease Control and Prevention (CDC) developed a suite of evidence-based lifestyle-change programs (LCPs) that provide preventive services through community organizations (eg, the YMCA). The Diabetes Prevention Program (DPP) was established in 2010 and is an evidenced-based LCP designed to prevent or delay the onset of type 2 diabetes (12). The CDC-approved curriculum — written at the 6th-grade reading level — is a year-long program instructed by lifestyle coaches with the goal of helping participants achieve a healthier lifestyle that encompasses nutrition changes, increased physical activity, and stress reduction (12). The DPP has demonstrated that lifestyle changes can be more effective than prescription medication to prevent or delay the onset of type 2 diabetes (13). The DPP Research Group found that 58% of people with prediabetes and 71% of people aged older than 60 years were able to meet the goal of decreasing body weight by 5% to 7% (14). Virtual DPP programs have helped people to meet weight-loss goals, especially people with low incomes and prediabetes who may not be able to attend in-person LCPs (13). The blood pressure self-monitoring program is a 4-month program developed by CDC to help participants measure their blood pressure correctly and consistently and educate them on healthy eating. Self-monitoring of blood pressure is supported by numerous national agencies (eg, American Heart Association) and can improve the management of hypertension (15).

Despite the evidence base for these programs, not everyone has an equal opportunity to access and succeed in these programs. Barriers to enrollment and participation exist, such as poor access to nutritious foods, few safe environments for physical activity, lack of transportation to programs, lack of reliable internet access or technology, and lack of childcare. Such barriers disproportionately affect Black people and families and may contribute to disparities in enrollment, retention, and success in LCPs (16). Screening for social needs allows providers to clearly identify barriers faced by program participants and determine how to effectively intervene. Interventions that alleviate unmet needs through screening, referral, and tracking of patients are imperative to increasing enrollment and success in LCPs (17).

Purpose and Objectives

The Alliance program was formed across multiple community-based health organizations in the St. Louis metropolitan area to design, test, and evaluate innovations that will optimize health status and advance racial equity. A major focus of the Alliance was to improve the reach of LCPs, particularly among Black residents living in the federally designated Promise Zone. Promise Zones are high-poverty, often medically underserved communities where the federal government partners with local leaders to enhance public health (18). These areas were formed by centuries of racial prejudice that resulted in migration patterns, both voluntary and forced, and territorial acquisition that led to the concentration of racial and ethnic minority groups (19). The largest of 22 Prom-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

ise Zones in the US, the St. Louis regional Promise Zone comprises 25 zip codes in the northern region of the city and county, an area that is home primarily to Black residents.

The objective of this article is to describe the process and preliminary outcomes of the implementation and evaluation of the Alliance program. It will provide insight and describe lessons learned on addressing interpersonal and structural barriers to improving antiracist efforts in chronic disease prevention and summarize factors that affected the ability of the Alliance to refer and enroll members of a racial minority group, specifically low-income Black people, in LCPs.

Intervention Approach

The Alliance is a partnership among the Missouri Department of Health and Senior Services, the St. Louis County Department of Public Health, the City of St. Louis Department of Health, the Integrated Health Network, the Missouri Primary Care Association, the Missouri Pharmacy Association, Fit and Food Connection, and the Gateway Region YMCA (Figure). The partnership was funded by CDC's Division of Diabetes Translation DP18-1817 project, a 5-year cooperative agreement, which launched October 1, 2018, and ends September 30, 2023. The project funds health departments to develop new and innovative approaches to increase the reach and effectiveness of evidence-based public health strategies in populations and communities with a high burden of diabetes, heart disease, and stroke (20).

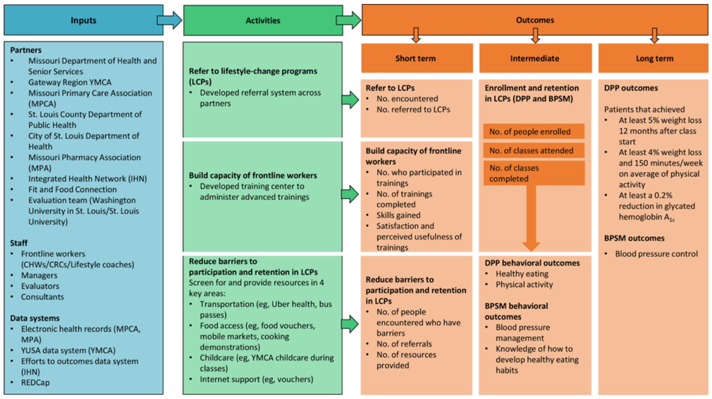


Figure. The Alliance logic model. Abbreviations: BPSM, blood pressure self-monitoring; CHW, community health worker; CRC, community resource coordinator; DPP, Diabetes Prevention Program; IHN, Integrated Health Network; LCP, lifestyle change programs; MPA, Missouri Pharmacy Association; MPCA, Missouri Primary Care Association; REDCap, Research Electronic Data Capture; YMCA, Young Men's Christian Association; YUSA, YMCA of the United States of America.

The main provider of the national DPP program and other LCPs (eg, the blood pressure self-monitoring program) in St. Louis is the Gateway Region YMCA. The Alliance supports community health workers and community resource coordinators, referred to as frontline workers, at partner organizations to screen patients for diabetes and hypertension risk and make referrals to LCPs. Lifestyle coaches, also considered frontline workers, facilitate programs and further support patients once they are enrolled in a program. Lifestyle coaches work with community health workers, community resource coordinators, and a community health navigator, who is embedded in the YMCA, to address social needs throughout the program with the goal of supporting people to complete the 12-month DPP.

Assessing and addressing social needs

The Alliance program developed a system to identify social barriers that may challenge full participation and success in LCPs. The system allows frontline staff at partner organizations to direct participants to other community programs and resources (eg, food assistance programs) that support health and well-being. For those who enroll in an LCP, the Alliance provides access to food vouchers, YMCA memberships, cooking and wellness-related classes, transportation subsidies, and onsite childcare to improve equity in enrollment, retention, and completion. Community health workers and partner organizations created a list of resources and a process for recommending, using, or accessing these resources to address patient barriers to participation.

Training center for frontline staff

The Alliance also built the capacity of frontline staff to interact with people disproportionately affected by chronic diseases, specifically Black residents, in community and clinical settings without the intention of inflicting interpersonal racism. To support a well-rounded and versatile workforce and offer high-quality training opportunities, the Alliance launched a training center in year 2.

Participation in training modules was not required of frontline staff but was strongly encouraged. Project staff created an online hub to notify frontline staff of training opportunities. A bootcamp-style training, including an introduction to relevant partners, resources, and procedures, was developed to orient frontline staff to the Alliance project. This training is now required of all new frontline staff and remains available for staff to take multiple times if needed.

Evaluation Methods

The Alliance used a strategic evaluation planning process for its evaluation. This process facilitates a transparent, logical, and participatory approach for assessing program and project-level out-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

comes (21). The strategic evaluation planning process involved 2 key groups throughout planning and evaluation: 1) program operators (eg, coalition partners, staff) and 2) primary users of the evaluation (eg, sponsors, collaborators, managers, partners). In year 1 (October 2018–September 2019), the Alliance evaluation team worked collaboratively with each partner to set up equitable data collection and reporting systems tailored to each organization while ensuring the collection of information needed for the overall evaluation. Outcomes were selected to align with 1) the goal of increasing the number of people, especially Black people, referred to, enrolled in, and successful in LCPs and 2) each organization's reporting systems and capacity to ensure that data collection and reporting were realistic and sustainable.

Quarterly data report. The team created a quarterly data report that aggregated information from each partner and communicated progress toward program goals. In this highly collaborative, multipartner program, consisting of many interrelated strategies, these data reports provided a mechanism for the Alliance leadership to manage risks and challenges that could impede successful implementation. Quarterly data reports were presented in all-partner meetings, distributed by email, and uploaded to a shared drive, which gave partners on-demand access to information on the progress and results of the evaluation project.

Referral system. The project team used REDCap (Research Electronic Data Capture) software hosted at Washington University in St. Louis. REDCap is a secure, web-based software platform designed to support data capture for research studies. We developed an electronic form and database in REDCap that launched in January 2020 and allowed all Alliance partners to make referrals to the YMCA through a common pathway. The referral form included information about the frontline staff member making the referral and their Alliance organization to allow for tracking at the organization level and allow the YMCA to communicate with the referring organization about the status of the person referred (eg, whether they enrolled, were actively engaged, or completed the program). The YMCA monitored referrals via REDCap in real time and used the system to track enrollment information and patient demographic data.

Addressing social needs and averting interpersonal racism. In addition to the referral system and quarterly data reports, the evaluation team used quantitative and qualitative approaches to examine 2 key strategies used by the Alliance: 1) accounting for social needs and barriers to participation and 2) building the capacity of frontline staff to interact with racial and ethnic minority populations in ways that do not inflict interpersonal racism. The referral system allowed frontline staff to document 4 barriers to participation identified by the Alliance partners as key to enrolling and being successful in LCPs: lack of transportation, food insecurity, lack of reliable internet, and childcare needs. Each organization had its own method for assessing social needs.

Focus group. Ten months after launching the referral system, the evaluation team conducted a focus group with frontline staff to understand the challenges of discussing, documenting, and addressing barriers to participation and making referrals to LCPs. The focus group was conducted virtually during the regular bimonthly meeting of frontline staff. Questions were developed to gain insight into the experiences of the frontline staff during their encounters with patients. Questions addressed social barriers that affect patients' ability to stay healthy, challenges in assessing unmet social needs, resources for patients' needs, and sustainability of assessing social needs after the Alliance project ends. The session was recorded and transcribed verbatim for analysis. Additionally, interactive all-partner activities were conducted throughout the project to refine processes across organizations. For example, frontline staff and managers from all partner organizations participated in mapping referral pathways and amending language on the referral form to better fit the needs of partners.

Training center. To evaluate the training center, project staff monitored participation in each training module and provided participants with a pre- and postsurvey to measure short-term changes in knowledge and frontline staff perception of training module effectiveness. Additionally, annual surveys were distributed to all participants to assess long-term maintenance and application of knowledge and skills. These annual surveys included open-ended questions to allow for qualitative responses. Data quality issues emerged with the pre- and postsurvey collection due to changes in the implementation platform. As a result, presurvey and postsurvey results are not reported. For this evaluation, we have results only for the annual survey conducted in September 2021, during year 3 (October 2020–September 2021). Year 4 (October 2021–September 2022) and year 5 (October 2022–September 2023) annual surveys had not been administered at the time of this writing. Barriers and facilitators of developing and implementing the training center were documented through informal discussions with relevant program staff and managers.

Evaluation framework

We used the Practical, Robust Implementation, and Sustainability Model (PRISM) to consider the dimensions of reach, effectiveness, adoption, and implementation and how they are influenced by multiple levels (ie, person, intervention, clinic or organization, and environment) (22). Year 1 of the 5-year project was used for hiring, planning, and establishing evaluation processes and systems for engaging the community and making referrals to LCPs.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Outcomes for all 5 years of the project were guided by the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) outcomes, which are part of the PRISM framework (Table 1). Reach was assessed as the absolute number of people encountered, defined as an interaction between an Alliance frontline staff member and a community member who could benefit from an LCP. A referral is a result of an encounter whereby a connection to LCPs is provided to the participant. The reach of the training center was examined as the number and proportion of frontline staff who participated in trainings. Effectiveness was defined as making referrals and enrolling people, especially those in the Promise Zone, in LCPs, and providing support for unmet social needs. The effectiveness of the training center was assessed as skills gained from trainings. Adoption was operationalized at the organizational level to understand which partners were participating in referrals and trainings. In the future, evaluation data will allow examination of retention and success (eg, improvements in health behaviors and outcomes) of program participants who received referrals (Figure). Additionally, the evaluation team will examine whether people who received the needed social support (through community resources, vouchers, etc) had better participation, retention, and success in the program than people who did not receive such support. As highlighted in PRISM, it was critical to realize the importance of context when examining the implementation of the Alliance project because it aimed to coalesce multiple organizations, each of which had its own resources, systems, cultures, and setting.

Data analysis

We used descriptive statistics and SAS version 9.4 software (SAS Institute Inc) to analyze all quantitative data. A single rater used rapid qualitative analysis methods (23) to analyze qualitative data (focus group, meetings, training center surveys); these methods were validated by other evaluation team members. The qualitative data from the focus group were analyzed by using a priori codes based on the interview guides. Two team members read through and coded the text from the discussion and then talked through discrepancies for reliability. Themes were derived from the coded text and summarized. Thematic summaries were aggregated into a brief and presented to Alliance partners.

Results

Referral and enrollment

The Alliance had 15 frontline staff members during the study period (January 2020–September 2022), with an average of 13 per year across partners. These staff members engaged with 6,036 people. Engagement increased as capacity (eg, number of frontline staff members, training, partnerships) increased (Table 2). On average, each frontline staff member engaged 234 people annually. Of the people encountered from January 2020 to September 2022, 847 (14%) were referred to the YMCA for an LCP (approximately 25 referrals per month). All 7 Alliance organizations referred community members to the YMCA. Referred people were aged on average 54.7 years (Table 3). Most (78%) were female and living in the Promise Zone (55%); 21% were food insecure, 15% had transportation needs, 3% needed childcare support, and 30% had unreliable internet.

Of those who were referred by Alliance frontline staff, 257 (30%) were eligible and enrolled in an LCP. Of these, 188 enrolled in the DPP and 76 enrolled in the blood pressure self-monitoring program; 7 people enrolled in both programs. On average, those who enrolled were aged 55.3 years. Most (92%) were female, 45% lived in the Promise Zone, 14% were food insecure, 9% had transportation needs, 1% had childcare needs, and 31% had unreliable internet (Table 3).

Focus group

Six of 15 Alliance frontline staff members participated in the focus group. Two main themes emerged from the data (Table 4). First was the importance of the frontline staff to the Alliance efforts. They described their work as “relationship-building” with patients and indicated they felt comfortable asking them about unmet social needs. They also reported serving as a resource person for many of their patients’ needs, often joining forces with each other to find resources that fit. The frontline staff noted that a main responsibility is to help patients prioritize and address stressors such as immediate obstacles and identify resources in a scarce environment. They mentioned the importance of consistent updates with patients on progress for obtaining resources, so they can move to the point where they might consider an LCP. The second theme from the focus group was barriers to patient health. The frontline staff discussed how many of their patients are focused on survival and not on healthy eating or even disease prevention. They noted that patients without basic necessities “can’t even see that as a goal,” which makes it difficult to refer them to an LCP. These barriers to patient health were amplified by the impact of the COVID-19 pandemic. The frontline staff talked about creating a place where they could share information on resources to provide to their patients and develop a cohort among themselves to “share stories and information” that might make their job easier. In the end, they reported that this could help patients be able to address their unmet needs.

Training center

In year 3, a total of 13 frontline staff members participated in trainings offered by the training center (Table 5). Of the 13 parti-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

cipants, 6 worked for the Missouri Primary Care Association, 2 worked for the Integrated Health Network, 1 worked for the St. Louis County Department of Public Health, 2 worked for the Gateway Regional YMCA, and 2 worked for the City of St. Louis Department of Health. On average, trainees completed 4.2 training modules during year 1. Of the training modules offered in year 3, three addressed health equity, 1 addressed trauma-informed care, 2 addressed mental health, 3 addressed health literacy, and 3 addressed racial equity.

Trainees reported gaining several skills from the modules, including the ability to understand their role in the Alliance and monitor personal bias. Trainees also developed interpersonal and professional skills, including de-escalating crisis situations, fulfilling mandates for reporting, educating patients on mental health, and monitoring patients' exercise and health. Lastly, trainees developed skills to understand the influence of community and environmental factors on health equity. When asked how these skills would affect their ability to refer patients, trainees reflected on asking appropriate questions, understanding correct procedures, communicating their role to patients, and referring patients to appropriate LCPs and community resources. One trainee commented that the training modules helped them engage with patients in an "unconventional" way by considering their "interests, values, and culture."

Implications for Public Health

Lessons learned from implementation and evaluation can inform other complex partnerships between clinical and community-based organizations to reduce barriers stemming from interpersonal and structural racism and increase enrollment and retention in LCPs of people disproportionately affected by chronic diseases. This 5-year real-world intervention has several public health implications. Enrolling and retaining Black people in community- and evidence-based LCPs can reduce the unequal burden of chronic disease (24). The project provided an opportunity to document evaluation and implementation facilitators and barriers that may apply to future public health efforts. We have summarized lessons learned and potential strategies for improvement.

Understanding context and complexity

The Alliance is a partnership of multiple health organizations with various structures, systems, cultures, and priorities. Implementation science frameworks such as the Consolidated Framework for Implementation Research (CFIR) illustrate the multilevel factors within and outside an organization that affect implementation (25). The Alliance used an intentional, participatory implementation and evaluation planning approach to understand each partner's current systems and ensure that the intervention and evaluation fit the context of each organization. This fit also included gaining an understanding of each organization's workflow and employee responsibilities. The evaluation was planned in collaboration with our partners to leverage existing data and expand their capacity for systematic and rigorous data collection. Each organization had multiple people in 2 key roles for implementation: managers and frontline staff. Developing communication structures that ensured all implementers and evaluators had a common understanding of the Alliance goals, implementation processes, and requirements for data reporting was critical. For example, frontline staff members were encouraged to provide feedback immediately after each training module, which helped the project manager and evaluators amend topics and modalities for subsequent training modules and evaluations. Compounding the implementation and evaluation was the evolution of systems, processes, priorities, and people throughout the project period, which likely was heightened by the COVID-19 pandemic. Changes in data collection methods and platforms affected data consistency and quality (eg, pre- and post-survey data from the training center were not usable). Furthermore, COVID-19 placed unforeseen demands on Alliance partners that left staff stretched thin and unable to fully complete the planned project and evaluation activities within the intended time frame.

When working with racial and ethnic minority populations who are potential participants in LCPs, it is also critical to understand the context (eg, environments) and complexity (eg, life situations, competing demands, diverse needs) of their lived experience that translate into barriers to meeting their needs. Our frontline workers were valued members of the community; they understood and established trust in the community. Having nonjudgmental, truthful conversations about social needs allowed for meaningful intervention. On the other hand, the context of each encounter (eg, limited time, lack of privacy) was not always suitable for certain conversations or referral to an LCP.

Developing collective, multilevel buy-in and prioritization

Partnerships between community- and clinic-based organizations and researchers offer an opportunity to bring scientific and practice-based knowledge and experience together to improve the quality, value, and relevance of implementing interventions. To achieve meaningful public health impact, a diverse set of clinical and community programs and partners is needed (26). Residents must use multiple assistance and intervention resources to ensure their needs are met (27). To this end, the Alliance comprises various organizations (eg, clinics, health departments, community-based organizations, universities) and multiple partners with various roles (eg, implementers, managers, evaluators, funders). The effective delivery of interventions requires engagement and buy-in

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

at multiple levels. The field of implementation science has emerged as a response to the challenges in translating evidence-based practices to real-world settings (28,29). Attention is paid to pre-implementation, which is the work necessary to effectively engage organizations and staff. Co-development of project goals, particularly with frontline staff, from inception may have generated stronger commitment and understanding of Alliance goals. Furthermore, clearly communicating implementation and evaluation expectations for each partner is vital to success. One facilitator of the Alliance's success in generating buy-in was the quarterly data report, which was disseminated via email and a shared drive and presented in all-partner meetings. These reports allowed partners to review collective progress and how this progress contributed to common goals. Additionally, the bootcamp-style training helped communicate project goals and structure to new Alliance members. Our intention was not to rigorously study these strategies; however, such a study could contribute to the field of implementation science by expanding the understanding of the mechanisms of change and the effectiveness of these discrete, multifaceted, and tailored strategies (30).

Being flexible and adapting

The Alliance evolved and responded to consequences of the COVID-19 pandemic in both engagement and service delivery. The COVID-19 pandemic started in year 2 (October 2019–September 2020) of this project, causing major shifts in priorities and resources as partners re-allocated staff to respond. Despite these shifts, engagement and enrollment in our programs increased, albeit slightly, each year. Although the main goal of the Alliance was maintained throughout the pandemic, flexibility was needed not only from partners but also from project funders, evaluators, and leadership. Some planned activities were delayed, while others sped up to support the community during the public health crisis. For example, an original program goal was to develop an online telehealth platform for DPP participants in year 4 (October 2021–September 2022). This goal was expedited. In year 3, we offered new remote classes, such as a lunchtime 30-minute exercise class and FitBit challenges, to all LCP enrollees. In addition to an online DPP course that was delivered by lifestyle coaches in a synchronous format, the Alliance piloted a self-paced online DPP program for 22 people. As a result of the effectiveness and acceptability among pilot participants, the Alliance opened referrals to anyone interested in this program. The community members' feedback was invaluable in developing this program.

Virtual LCPs became the only option for participating in an LCP during the COVID-19 pandemic. Virtual classes can improve access for people with transportation or time barriers or limited access to technology devices or reliable broadband internet. Frontline staff were primed with resources (eg, the Affordable Connectivity Program offered by the Federal Communication Commission, library hotspots) to support people without internet access or in places with poor connectivity. Enrollees were further supported by lifestyle coaches. Infrastructure changes and additional resources are needed to fully support these people and improve digital literacy among populations who may not be comfortable using technology (eg, older persons).

Another example of the impact of the COVID-19 pandemic was flexibility in recruitment methods. Before the pandemic, community members were encountered primarily through in-person clinic visits, community events, and health fairs. During the pandemic, the Alliance shifted strategies to reach people remotely (eg, via telehealth, telephone) and launched a marketing campaign that promoted LCPs at transit stops and via social media. The Alliance leveraged increases in drive-through food distributions by including flyers about the Alliance program and the DPP in food boxes. The Alliance also increased community awareness of food resources by building a website that provides details of mobile grocery vendors and other food access opportunities.

Another adaptation to the COVID-19 pandemic was to change frontline staff trainings to a flexible, self-paced format and add COVID-19–related material (eg, a training titled "Understanding Health Disparities in Heart Disease in these Unsettling Times"). The Alliance also pivoted to support the needs of communities and partners. For example, frontline staff in clinical settings received training in a COVID-19 vaccine module to assist community members who were not vaccinated and had questions about the vaccine. To maintain project goals, vaccine appointments were leveraged as an opportunity to screen and assist with unmet social needs, particularly because these needs had increased during the pandemic among racial and ethnic minority groups.

Evaluating a constantly adapting project was a challenge. These adaptations required bidirectional communication with implementers and project managers to ensure progress toward intended goals. Annual documentation of progress was also required by the funder. Collaborative relationships between the Alliance evaluation team and partners were key to overcoming this challenge.

Keeping an eye to the future

To fully realize public health impact, we should broadly and equitably sustain effective public health programs and partnerships; this sustainment requires active and early planning (31). The Alliance evaluation will use a participatory design approach for developing a sustainability plan and generating capacity for sustainability. Sustainability capacity, defined as the ability to maintain systems and their benefits over time, may be influenced by 8 domains out-

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

lined in the sustainability framework: environmental support, funding stability, partnerships, organizational capacity, program evaluation, program adaptation, communications, and environmental support (32,33). To build capacity, it is necessary to systematically assess and understand factors affecting a program's sustainability capacity and develop a sustainability plan with actionable strategies. The Alliance will use a mixed-methods, partner-engaged approach involving quantitative surveys and qualitative interviews. We first want to understand perceived barriers (eg, resources, time) and facilitators within these 8 domains to continue the Alliance partnership and referral system. The use of such an approach to ensuring sustainability is essential to public health impact and is required by many public health agencies and foundations (eg, CDC, Robert Wood Johnson Foundation, Kaiser Permanente).

Conclusion

Responding to complex health inequities in communities requires collaborative partnerships. The Alliance is an example of how health care, public health, and community partners work together to increase recruitment and enrollment of racial and ethnic minority populations who are disproportionately affected by chronic diseases into evidence-based LCPs. Solely increasing access to these programs may not achieve the desired effect. The Alliance also aims to address interpersonal and structural racism that may generates barriers (eg, structural barriers to food access, physical activity facilities, childcare, and transportation) that impede equitable health improvements. The Alliance evaluation shows that strong collaborative relationships among partners and the co-development of systems and priorities can achieve positive outcomes.

Acknowledgments

This work was supported by the Prevention Research Center at Washington University in St. Louis (no. U48DP006395) and CDC 1817 grant no. HE2021-0202. We acknowledge the contribution of all Alliance partners who contributed to the implementation and evaluation of this project: the Missouri Department of Health and Senior Services, the St. Louis County Department of Public Health, the City of St. Louis Department of Health, the Integrated Health Network, the Missouri Primary Care Association, the Missouri Pharmacy Association, the Fit and Food Connection, and the Gateway Region YMCA. REDCap was used to support capture of data. No copyrighted materials were used in this research or article.

Author Information

Corresponding Author: Maura M. Kepper, PhD, Prevention Research Center, Washington University in St. Louis, 1 Brookings Dr, Campus Box 1196, St. Louis, MO 63130 (kepperm@wustl.edu).

Author Affiliations: [1]Prevention Research Center, Washington University in St. Louis, St. Louis, Missouri. [2]College for Public Health and Social Justice, Washington University in St. Louis, St. Louis, Missouri. [3]St. Louis County Department of Public Health, St. Louis, Missouri. [4]City of St. Louis Department of Health, St. Louis, Missouri. [5]Fit and Food Connection, St. Louis, Missouri. [6]Gateway Region YMCA, St. Louis, Missouri. [7]Missouri Department of Health and Senior Services, Bureau of Cancer and Chronic Disease Prevention, Jefferson City, Missouri.

References

1. Raghupathi W, Raghupathi V. An empirical study of chronic diseases in the United States: a visual analytics approach. Int J Environ Res Public Health 2018;15(3):431.
2. Glantz NM, Duncan I, Ahmed T, Fan L, Reed BL, Kalirai S, et al. Racial and ethnic disparities in the burden and cost of diabetes for US Medicare beneficiaries. Health Equity 2019; 3(1):211–8.
3. Holman HR. The relation of the chronic disease epidemic to the health care crisis. ACR Open Rheumatol 2020;2(3): 167–73.
4. Centers for Disease Control and Prevention. Type 2 diabetes. Last reviewed December 30, 2022. Accessed October 25, 2022. https://www.cdc.gov/diabetes/basics/type2.html
5. City of St. Louis Department of Health, Center for Health Information, Planning, and Research. Diabetes data brief. 2021. Accessed October 25, 2022. https://www.stlouis-mo.gov/government/departments/health/documents/briefs/upload/Diabetes-Data-Brief-1-7-2021.pdf
6. Chow EA, Foster H, Gonzalez V, McIver L. The disparate impact of diabetes on racial/ethnic minority populations. Clin Diabetes 2012;30(3):130–3.
7. Kepper MM, Walsh-Bailey C, Prusaczyk B, Zhao M, Herrick C, Foraker R. The adoption of social determinants of health documentation in clinical settings. Health Serv Res 2023; 58(1):67–77.
8. Paradies Y, Ben J, Denson N, Elias A, Priest N, Pieterse A, et al. Racism as a determinant of health: a systematic review and meta-analysis. PLoS One 2015;10(9):e0138511.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

9. Haw JS, Shah M, Turbow S, Egeolu M, Umpierrez G. Diabetes complications in racial and ethnic minority populations in the USA. Curr Diab Rep 2021;21(1):2.
10. Tan TW, Shih CD, Concha-Moore KC, Diri MM, Hu B, Marrero D, et al. Disparities in outcomes of patients admitted with diabetic foot infections. PLoS One 2019;14(2):e0211481.
11. Meng Y-Y, Diamant A, Jones J, Lin W, Chen X, Wu SH, et al. Racial and ethnic disparities in diabetes care and impact of vendor-based disease management programs. Diabetes Care 2016;39(5):743–9.
12. Centers for Disease Control and Prevention. National Diabetes Prevention Program. Last reviewed December 27, 2022. Accessed October 25, 2022. https://www.cdc.gov/diabetes/prevention/index.html
13. Kim SE, Castro Sweet CM, Cho E, Tsai J, Cousineau MR. Evaluation of a digital diabetes prevention program adapted for low-income patients, 2016–2018. Prev Chronic Dis 2019;16:E155.
14. Knowler WC, Barrett-Connor E, Fowler SE, Hamman RF, Lachin JM, Walker EA, et al; Diabetes Prevention Program Research Group. Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. N Engl J Med 2002;346(6):393–403.
15. Shimbo D, Artinian NT, Basile JN, Krakoff LR, Margolis KL, Rakotz MK, et al; American Heart Association and the American Medical Association. Self-measured blood pressure monitoring at home: a joint policy statement from the American Heart Association and American Medical Association. Circulation 2020;142(4):e42–63.
16. Connell CL, Wang SC, Crook L, Yadrick K. Barriers to healthcare seeking and provision among African American adults in the rural Mississippi Delta region: community and provider perspectives. J Community Health 2019;44(4):636–45.
17. Ruiz Escobar E, Pathak S, Blanchard CM. Screening and referral care delivery services and unmet health-related social needs: a systematic review. Prev Chronic Dis 2021;18:E78.
18. US Department of Housing and Urban Development. Promise Zones overview. Accessed September 27, 2022. https://www.hudexchange.info/programs/promise-zones/promise-zones-overview
19. Eberth JM, Hung P, Benavidez GA, Probst JC, Zahnd WE, McNatt MK, et al. The problem of the color line: spatial access to hospital services for minoritized racial and ethnic groups. Health Aff (Millwood) 2022;41(2):237–46.
20. Centers for Disease Control and Prevention. DP18-1817. Last reviewed December 9, 2022. Accessed May 2, 2023. https://www.cdc.gov/diabetes/programs/stateandlocal/funded-programs/dp18-1817.html
21. Centers for Disease Control and Prevention, National Center for Environmental Health, Division of Environmental Health Science and Practice, Asthma and Community Health Branch. Learning and growing through evaluation: asthma program evaluation guide. Module 2: implementing evaluations. January 2021. Accessed October 25, 2022. https://www.cdc.gov/asthma/program_eval/asthmaprogramguide_mod2.pdf
22. McCreight MS, Rabin BA, Glasgow RE, Ayele RA, Leonard CA, Gilmartin HM, et al. Using the Practical, Robust Implementation and Sustainability Model (PRISM) to qualitatively assess multilevel contextual factors to help plan, implement, evaluate, and disseminate health services programs. Transl Behav Med 2019;9(6):1002–11.
23. Gale RC, Wu J, Erhardt T, Bounthavong M, Reardon CM, Damschroder LJ, et al. Comparison of rapid vs in-depth qualitative analytic methods from a process evaluation of academic detailing in the Veterans Health Administration. Implement Sci 2019;14(1):11.
24. Hill-Briggs F, Adler NE, Berkowitz SA, Chin MH, Gary-Webb TL, Navas-Acien A, et al. Social determinants of health and diabetes: a scientific review. Diabetes Care 2020;44(1):258–79.
25. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci 2009;4(1):50.
26. Brennan Ramirez LK, Baker EA, Metzler M. Promoting health equity: a resource to help communities address social determinants of health. Centers for Disease Control and Prevention; 2008. Accessed October 25, 2022. https://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/tools/pdf/sdoh-workbook.pdf
27. Chapman D, McKelvey B, Bennett C, Carlos Chavez FL, Hermsen J, Rikoon JS. Food assistance and hunger in the Heartland 2021: report for the St. Louis Area Foodbank. Columbia (MO): Interdisciplinary Center for Food Security, University of Missouri; 2022.
28. Brownson RC, Colditz GA, Proctor EK. Dissemination and implementation research in health: translating science to practice. 2nd ed. Oxford University Press; 2018.
29. Eccles MP, Mittman BS. Welcome to Implementation Science. Implement Sci 2006;1(1):1.
30. Powell BJ, Fernandez ME, Williams NJ, Aarons GA, Beidas RS, Lewis CC, et al. Enhancing the impact of implementation strategies in healthcare: a research agenda. Front Public Health 2019;7:3.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

31. Kwan BM, Brownson RC, Glasgow RE, Morrato EH, Luke DA. Designing for dissemination and sustainability to promote equitable impacts on health. Annu Rev Public Health 2022; 43(1):331–53.
32. Calhoun A, Mainor A, Moreland-Russell S, Maier RC, Brossart L, Luke DA. Using the Program Sustainability Assessment Tool to assess and plan for sustainability. Prev Chronic Dis 2014;11:130185.
33. Schell SF, Luke DA, Schooley MW, Elliott MB, Herbers SH, Mueller NB, et al. Public health program capacity for sustainability: a new framework. Implement Sci 2013;8(1):15.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Tables

Table 1. Outcomes Guided by the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) Framework in an Evaluation of a Project to Increase Participation of Black People in Evidence-Based Lifestyle-Change Programs, St. Louis, 2018–2023[a]

RE-AIM construct	Outcomes	Data sources
Reach	The absolute number of community members who were encountered (years 2–4)	Quarterly data reports; REDCap referral system
	The absolute number and proportion of frontline staff who participated in trainings (year 3)	REDCap Training Center survey
Effectiveness	The absolute number, proportion, and representativeness of community members referred and enrolled (years 2–4)	REDCap referral system
	Skills gained from trainings (year 3)	REDCap Training Center survey
Adoption	The absolute number and proportion of Alliance organizations that made referrals and participated in trainings (years 2–4)	REDCap referral system; REDCap Training Center survey
Implementation	Barriers and facilitators to implementing and evaluating the Alliance programs (eg, making referrals, addressing social needs, training frontline staff) (years 1–4)	Process data; focus groups

[a] The study period was January 2020–September 2022. The project was funded by the Centers for Disease and Control’s Division of Diabetes Translation DP18-1817 project, a 5-year cooperative agreement, which launched October 1, 2018, and ends September 30, 2023.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors’ affiliated institutions.

Table 2. Engagement in a Project to Increase Participation of Black People in Evidence-Based Lifestyle-Change Programs, St. Louis, 2018–2023[a]

Phase	Year 2 (October 2018–September 2019)	Year 3 (October 2019–September 2020)	Year 4 (October 2020–September 2021)	Total
Engaged	1,917	1,915	2,204	6,036
Referred	317	230	300	847
Enrolled	50	99	108	257

[a] The study period was January 2020–September 2022. The project was funded by the Centers for Disease and Control's Division of Diabetes Translation DP18-1817 project, a 5-year cooperative agreement, which launched October 1, 2018, and ends September 30, 2023.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table 3. Representativeness of Participants in Lifestyle-Change Programs, St. Louis, 2018–2023[a]

Characteristic	Total referred (n = 847)[b]	Total enrolled (n = 257)[b]
Age		
Respondents to question	798 (94.2)	257 (100.0)
Mean (SD), y	54.7 (13.2)[c]	55.3 (13.1)[c]
Missing data	49 (5.8)	0
Sex		
Respondents to question	837 (98.8)	257 (100.0)
Male	179 (21.4)[c]	20 (7.8)[c]
Female	655 (78.3)[c]	237 (92.2)[c]
Unspecified	3 (0.4)[b]	0
Missing data	10 (1.2)	0
Reside in the Promise Zone[d]		
Respondents to question	799 (94.3)	257 (100.0)
Respondents who reside in Promise Zone	440 (55.1)[c]	115 (44.7)
Missing data	48 (5.7)	0
Social barriers to participation		
Lack of food access		
Respondents to question	568 (67.1)	228 (88.7)
Respondents with lack of food access	119 (21.0)[c]	33 (14.5)[c]
Missing data	279 (32.9)	29 (11.3)
Transportation needs		
Respondents to question	564 (66.6)	226 (87.9)
Respondents with transportation needs	83 (14.7)[c]	21 (9.3)[c]
Missing data	283 (33.4)	31 (12.1)
Childcare needs		
Respondents to question	564 (66.6)	227 (88.3)
Respondents with childcare needs	16 (2.8)[c]	3 (1.3)[c]
Missing data	283 (33.4)	30 (11.7)
Unreliable internet		
Respondents to question	482 (56.9)	227 (88.3)
No. (%) of respondents	144 (29.9)[c]	71 (31.3)[c]
Missing data	365 (43.1)	30 (11.7)

[a] The study period was January 2020–September 2022. The project was funded by the Centers for Disease and Control's Division of Diabetes Translation DP18-1817 project, a 5-year cooperative agreement, which launched October 1, 2018, and ends September 30, 2023.
[b] Unless otherwise indicated, values are number (percentage).
[c] Percentages are based on number of respondents who answered question.
[d] Promise Zones are high-poverty, often medically underserved communities where the federal government partners with local leaders to enhance public health (18).

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table 4. Themes and Example Quotes From Focus Groups With Alliance Frontline Staff in a Project to Increase Participation of Black People in Evidence-Based Lifestyle-Change Programs, St. Louis, 2018–2023[a]

Theme	Example quotes
Theme 1: Importance of frontline staff to Alliance efforts	I think one of the benefits of having community health workers screen for social determinants of health is that they are experts in developing that relationship and that rapport to be able to access information.
	It depends on that rapport that that CHW [community health worker] or CRC [community resource coordinators] or whoever originally builds with the patient. That carries a long ways. If you come off like you know everything, you will not get answers. You will get just what they want to tell you. You have to be a person to them.
	A lot of these things really affect people in ways that you might not think about unless you're really, really working with them every day.
Theme 2: Barriers to patient health	Our patients certainly struggle with transportation, food and childcare, but to me it's sometimes just the tip of the iceberg. There's all of the different adverse community experiences they've had. Discrimination, poverty. A lot of different traumatic events that they've experienced. And so, then that's just another layer we have to consider when we're helping them to work through transportation, food, childcare and other social determinants. Because there's always layers of social and structural determinants of health that we have to address.
	We have patients who don't have electric or gas, they don't have a refrigerator, they don't have some things that some people might consider basic. That's their starting point. So, we have to start at their starting point, which sometimes is not necessarily focusing on healthy eating. So, we try to help them get those needs met so we can get them to a starting point of focusing on health.

[a] The study period was January 2020–September 2022. The project was funded by the Centers for Disease and Control's Division of Diabetes Translation DP18-1817 project, a 5-year cooperative agreement, which launched October 1, 2018, and ends September 30, 2023.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.

Table 5. Summary of Trainings Completed, by Domain, in a Project to Increase Participation of Black People in Evidence-Based Lifestyle-Change Programs, St. Louis, 2018–2023[a]

Training name	Domain (no. of modules)					No. of participants per training module
	Health equity (n = 3)	Trauma-informed care (n = 1)	Mental health (n = 2)	Health literacy (n = 3)	Racial equity (n = 3)	
Unequal Treatment: Disparities in Access, Quality, and Care	X				X	7
No Safety, No Health: A Conversation about Race, Place and Preventing Violence		X			X	8
Let's Live Healthy! High Blood Pressure in Pregnancy				X		5
Mental Health and Wellness: Positive Psychology and Psychiatry in Uncertain Times			X			9
Understanding Health Disparities in Heart Disease in these Unsettling Times	X				X	7
The Importance of Measuring Blood Pressure Accurately				X		4
Understanding the Intersection of Diabetes and Addiction	X		X			7
Use of Social Media and Peer Support in Diabetes Care: A Panel from AADE Project Leaders				X		7

Abbreviation: AADE, Association of Diabetes Care & Education Specialists.

[a] The study period was January 2020–September 2022. The project was funded by the Centers for Disease and Control's Division of Diabetes Translation DP18-1817 project, a 5-year cooperative agreement, which launched October 1, 2018, and ends September 30, 2023.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.