PRINCIPLES OF COMMUNITY ENGAGEMENT

3RD EDITION

U.S. CENTERS FOR DISEASE
CONTROL AND PREVENTION
AGENCY FOR TOXIC SUBSTANCES
AND DISEASE REGISTRY

CS353949-B January 2025

Two federal government employees screen soil for lead during a community event. *ATSDR, 2016.*

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention, the Agency for Toxic Substances and Disease Registry, the National Institutes of Health (NIH), the NIH National Center for Advancing Translational Sciences, or the NIH National Institute of Environmental Health Sciences.

A visioning and planning community meeting. *ATSDR, 2016.*

ACRONYMS FREQUENTLY USED IN THIS DOCUMENT

AHF	Acute Heart Failure
ATSDR	Agency for Toxic Substances and Disease Registry
CAB	Community Advisory Board
CBPR	Community-Based Participatory Research
CCB	Morehouse School of Medicine Prevention Research Center Community Coalition Board
CDC	Centers for Disease Control and Prevention
CE	Community Engagement
CE Studio	Community Engagement Studio
CEAL	The Community Engagement Alliance Against COVID-19 Disparities
CEDC	[University of New Mexico] Center for Native Environmental Health Equity Research Community Engagement and Dissemination Core
CEnR	Community-Engaged Research
CERC	Community Engaged Research Core
C-M-O	Context, Mechanism, Outcome
COP	Community of Practice
CRECH	Center for Research on Ethnicity, Culture and Health
CREE	Culturally Responsive and Equitable Evaluation
CRHD	UC Davis Center for Reducing Health Disparities
CTSA	Clinical and Translational Science Awards Program
EBIs	Evidence-Based Interventions
GATES	Growing Appalachian Teens as Environmental Scientists
GCC	Graniteville Community Coalition
ICCTM	Solano County Interdisciplinary Collaboration and Cultural Transformation Model
IS	Implementation Science
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning
LHAs	Lay Health Advisors
MAPS	Measurement Approaches to Partnership Success
NAM	National Academy of Medicine”
NASEM:	National Academies of Science, Engineering and Medicine
NFN	Neighborhood Food Network
NGO	Non-Governmental Organization
NIEHS	National Institute of Environmental Health Sciences
NIH	National Institutes of Health
OVGG	Ocean View Growing Grounds
PCORI	Patient-Centered Outcomes Research Institute
PEPH	Partnerships for Environmental Public Health
PRC	Prevention Research Center
PVN	Patient Voices Network
RCA	Rapid Community Assessment
RE-AIM	Reach, Effectiveness, Adoption, Implementation, and Maintenance
RHCP	Rochester Healthy Community Partnership
SCBH	Solano County Behavioral Health
SDOH	Social Determinants of Health
SNA	Social Network Analysis
The R.I.S.E. Project	Restoration in Graniteville through Supportive Engagement
UIC	University of Illinois Chicago
UK-CARES	University of Kentucky Center for Appalachian Research in Environmental Sciences
UNM	University of New Mexico
UofSC	University of South Carolina
USC CEPHE	University of Southern California Community Engagement Program on Health and the Environment
VUMC	Vanderbilt University Medical Center
YPAR	Youth Participatory Action Research

ACKNOWLEDGMENTS

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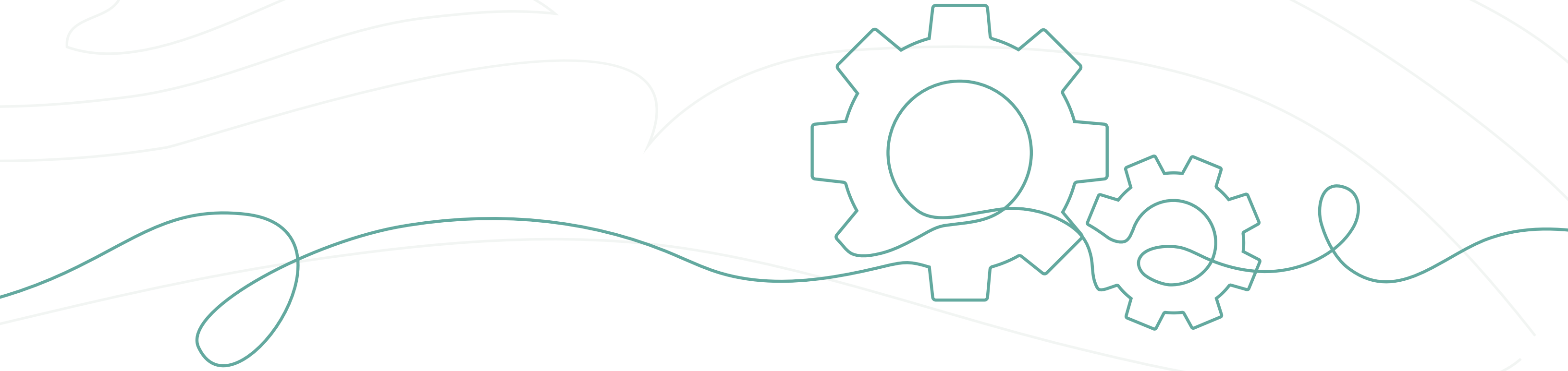
Over 165 individuals contributed to this, the third edition of *Principles of Community Engagement*. The findings and conclusions in this report are those of the authors and may not represent the official positions of the Centers for Disease Control and Prevention, the Agency for Toxic Substances and Disease Registry, the National Institutes of Health (NIH), the NIH National Center for Advancing Translational Sciences, or the NIH National Institute of Environmental Health Sciences.



WELCOME, READERS

With great pleasure, we invite you to read the *Principles of Community Engagement, 3rd Edition*. The third edition was released by the Agency for Toxic Substances and Disease Registry (ATSDR), in partnership with collaborators at the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and other organizations.

ATSDR serves as a science-based public health agency. Since 1980, we have been working to address community concerns about hazardous waste. During the past 44 years, ATSDR has worked in countless communities nationwide to address their environmental concerns and keep them safe from environmental hazards. We strive to be a trusted agency protecting American, tribal (Indigenous), and territorial communities from environmental health threats. We build trust through partnerships and by applying state-of-the-art science and effective community engagement. ATSDR's Office of Capacity Development & Applied Prevention Science (OCDAPS) translates science into tools and actions that individuals, communities, and organizations can apply to identify, reduce, or prevent health effects from exposures to hazardous substances.

We do not, and cannot, work alone. Therefore, we work closely with communities, partners, and professional organizations. We develop resources and tools for communities to take action to protect their health. We recommend actions that state and local health partners can take to address community concerns. We engage, develop trust, build rapport, and forge strong partnerships with communities. This is essential to advance our mission of protecting communities from harmful health effects related to exposure to natural and man-made hazardous substances.

The *Principles of Community Engagement, 3rd Edition*, is our newest endeavor on the forefront of building strong science in community engagement. The third edition builds upon the previous two editions (1997, 2011). This edition incorporates the latest science and places a strong focus on communities disproportionately burdened by health and exposure risks. The communities—often those with lower income and of racial and ethnic minority groups—live and work in areas affected by environmental exposures and with limited resources. These conditions profoundly affect their physical, mental, environmental, and economic health.

We hope you find this book helpful. We welcome you to join us and our partners in our quest to make communities healthy, beautiful, strong, and resilient!

Sincerely,

Christopher M. Reh, PhD
Associate Director
ATSDR

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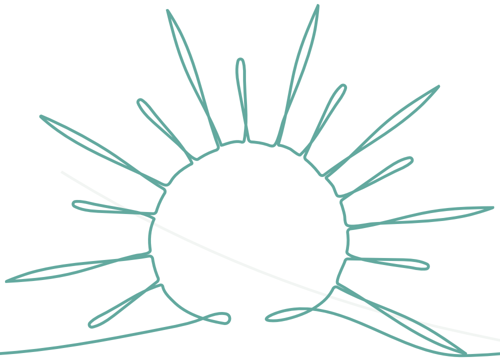

FOREWORD

Anyone who comes from a large family will tell you that life works best when we all pull together. Community engagement—pulling together—is at the heart of our work in the Department of Health and Human Services and with our partners. *Principles of Community Engagement*, now in its third edition, has been a seminal text spanning three decades of America pulling together, fostering partnerships, and working with communities to improve health. This third edition involves more than 100 volunteers from communities across the nation, strengthening community engagement to equitably improve all aspects of health, including physical and mental health and social, economic, and environmental health. All of this makes this edition more consequential than ever. Where we live, thrive, work, and play profoundly impacts our health. Are we surrounded by good schools, healthy food, and quality health centers? Can we feel safe letting our children drink the water from our taps, or walk home alone from school? Are we more or less connected today to the people who count in our lives?

Americans are falling ill too soon and dying too young from diseases that we know how to prevent and treat. Americans do not share this burden equitably. We live in a country where zip code predicts life expectancy. But when we all pull together through meaningful community engagement, families and neighborhoods can flourish and thrive.

The Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) published the first edition of *Principles of Community Engagement* in 1997. In 2011, CDC and ATSDR partnered with our scientific community to publish an expanded second edition. Partners included the National Institutes of Health, particularly the National Center for Advancing Translational Sciences (NCATS), Clinical and Translational Science Award (CTSA) program. The third edition recognizes how far we have come while acknowledging how far we must travel to achieve health equity.

The third edition aligns with the National Academy of Medicine by including a new model for community engagement. It adds a tenth principle on trust and recognizes that trustworthiness is essential for effective partnerships and advancing diversity, equity, and inclusion. This edition also includes examples from the many issues that have affected our communities, such as COVID-19, the opioid crisis, climate change, environmental justice, and the health of our land. It highlights ways to advance health equity through evaluation, implementation, and dissemination of science and information. In addition, it introduces new frameworks for measures, metrics, and evaluation.

Principles of Community Engagement, 3rd Edition will be helpful to all in public service, academic fields, health care, and the broad range of public health careers. This work honors those in diverse communities and public agencies, as it shows how we labor together to build trust and equitably improve health.

The third edition of *Principles of Community Engagement* speaks to who we are as a large, diverse, complex yet vibrant American family. Everyone in our family should have the opportunity for a healthy life. And every one of us must play a role, contributing as we say in Spanish "nuestro granito de arena"—our grain of sand—to build together the path to health and prosperity. *Principles of Community Engagement, 3rd Edition*, will serve as a reliable roadmap on that journey.

Xavier Becerra

25th Secretary of the U.S. Department of Health and Human Services (2024)

INTRODUCTION FROM DR. GEORGE MENSAH OF THE NATIONAL INSTITUTES OF HEALTH

Meaningful community engagement is at the core of successful community partnerships with health sector organizations and entities committed to promoting community health and wellbeing. As recognized by the U.S. National Academy of Medicine, "community engagement is not a single event or goal, but a complex, dynamic process that changes across time and location" and can lead to impactful, promising outcomes. The complexity and dynamism are best tackled when the core principles of community engagement are embraced, understood, and practiced. This is where I find this third edition of *Principles of Community Engagement* invaluable and refreshing. It is also exciting to see its new emphasis on trust, trustworthiness, and implementation science.

The crucial importance of trust in community engagement is one of the major lessons learned from the COVID-19 pandemic. At the National Institutes of Health (NIH), as we engaged racial and ethnic minority communities disproportionately impacted by the pandemic, a common exhortation was the need to "move at the speed of trust." Demonstrating trustworthiness and earning and maintaining the trust of all partners are foundational to impactful community engagement and to advancing diversity, equity, and inclusion. The importance of trust was recognized in the first edition of *Principles of Community Engagement* published in 1997, although it was not included as a core principle. It is wonderful to see that this third edition elevates trust and trustworthiness as part of a new core principle of community engagement.

Worldwide, we are faced daily with multiple examples of proven-effective health interventions that do not reach communities of people who need them most. This includes infants and children, mothers, young adults, older adults, and most persons in communities in low-resource settings who bear a disproportionate burden of acute and chronic diseases, injuries, and risk factors. Even in instances where these communities are meaningfully engaged and reached with proven-effective interventions, challenges of affordability, acceptability, and cultural appropriateness of the interventions limit the adoption and use of the desired intervention. The science of dissemination and implementation research provides theories, models, and frameworks that can help tackle these barriers, identify facilitators, and inform successful adoption, adaptation, and sustainment of proven-effective interventions. In this regard, this third edition of *Principles of Community Engagement* does not disappoint! It leverages the emerging science of equity-oriented implementation frameworks in community engagement for promoting health for all and advancing health equity.

Much progress has been made since the first edition of this book was published. However, the perennial problems of community engagement remain ubiquitous and continue to hamper the effectiveness and impact of community engagement. Among these are:

- The challenge of achieving and sustaining meaningful, authentic, and effective partnerships between research investigators, research institutions, and community-based organizations and other community partners
- Token engagement with little actual community influence on decision-making and priority outcomes
- Past research misdeeds, lack of transparency, and historical injustices that continue to breed mistrust
- Power imbalances that devalue community knowledge and expertise
- Limited community resources and capacity for research
- Cultural and linguistic barriers and inadequate or ineffective communication strategies
- Challenges with ownership, sharing, and use of the community's data and long-term sustainability of community engagement

At the NIH, we remain committed to advancing the principles of community engagement through active support of community-engaged research. A primary platform for this work is the NIH-wide Community Engagement Alliance (CEAL). This platform now comprises 21 CEAL Regional Research Teams and other programs across the United States, including

- An Alliance for Community Engagement in Climate and Health (ACE-CH)
- Community Engagement Consultative Resource (CEACR)
- Maternal Health Community Implementation Program (MH-CIP)
- Network for Community-Engaged Primary Care Research (NCPCR)
- The American Indian/Alaska Native, Native Hawaiian/Pacific Islander Enrichment Initiative (AIAN-NHPI-EI)
- The Health Knowledge Monitoring and Response System (HKMRS)
- The Community Engagement Alliance for Genomics Research (CEAL4Genomics).

The core thread that runs through all of these programs is meaningful engagement by research investigators who collaborate with more than 1,000 community partners, of which half are community-based organizations. These partners work together to promote community health and advance health equity. This third edition of the book will be invaluable to all CEAL programs. The book will also be essential for other NIH programs such as the Clinical and Translational Science Awards (CTSA) program, the Community Partnerships to Advance Science for Society (ComPASS) program, the Rapid Acceleration of Diagnostics in Underserved Populations (RADx-UP), the Helping to End Addiction Long-term (HEAL), the Cancer Moonshot, and the *All of Us* Research Program.

As I reflect on the essential principles in this book, it is clear that we are charting the future of NIH-supported, community-engaged research. As such, I am reminded to heed the African proverb: "If you want to go fast, go alone. If you want to go far, go together." This book offers us a unique opportunity to journey together, as trusted voices, thought leaders, and members of the communities we serve, to promote community health and advance health equity.

I commend the editors and the 165 authors who contributed chapters to this invaluable resource. The third edition will serve as a beacon of hope and an inspiration to generations of academic and community researchers; community-based organizations and other community partners; community thought-leaders; and federal, state, and local policymakers. I hope that you, as a reader, will embrace the principles in this book and practice them daily in your work as we journey together to create more equitable, resilient, and thriving communities.

George A. Mensah, MD, FACC

Director, Center for Translation Research and Implementation Science (CTRIS)

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DEVELOPING THE PUBLICATION

The work of the Clinical and Translational Science Awards (CTSA) Consortium's Community Committees helped develop the initial editions of the *Principles of Community Engagement*. Through a volunteer effort, multiple contributors developed the current, third edition. The current manuscript was collaboratively developed by members of the National Institutes of Health, the Agency for Toxic Substances and Disease Registry, the Centers for Disease Control and Prevention and other CTSA partners. Contributors to the project include university partners who led or contributed to the second edition in 2011, along with new authors and non-profit leadership and partners. No contributors were compensated for this effort. The publication is in the public domain and may be reprinted or copied without permission but with appropriate citation. The citation for this edition is Agency for Toxic Substances and Disease Registry. (2025, January 13).

ABOUT THE AUTHORS AND EDITORS

Many of the authors and editors are affiliated with the National Institutes of Health, the Centers for Disease Control and Prevention, and the Agency for Toxic Substances and Disease Registry. These agencies are part of the U.S. Department of Health and Human Services. The National Institutes of Health is the nation's medical research agency, making important medical discoveries that improve health and save lives (www.nih.gov). The Centers for Disease Control and Prevention is the nation's leading science-based, data-driven service organization that protects the public's health (www.cdc.gov). The Agency for Toxic Substances and Disease Registry is a federal public health agency. Its mission is to protect communities from harmful health effects related to exposure to natural and man-made hazardous substances (www.atsdr.cdc.gov).

In this third edition of *Principles of Community Engagement*, we have welcomed contributions from community engagement researchers and their community partners. Our editors are also authors in this third edition. All authors and editors volunteered their time to create the third edition. With over 165 contributors, we are most proud to present the third edition. The findings and conclusions in each chapter and the overall manuscript are those of the authors and may not represent the official positions of the National Institutes of Health, the Centers for Disease Control and Prevention, or the Agency for Toxic Substances and Disease Registry.

CHAPTER 1: COMMUNITY ENGAGEMENT—DEFINITIONS AND KEY CONCEPTS

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The Landscape

This chapter reviews changes in society and culture over the past decade and how we as a society view the value and contribution of community engagement. These changes shine a spotlight on the increased and vital need for community engagement as there is:

1) **Increased recognition that both the health care system and the conditions within which people live, learn, work, play, and pray—called the social determinants of health—affect health.**
2) **Greater awareness about historic or current inequities, prompting a renewed social justice movement. This movement highlights the role of policies, practices, and organizational structures that may unfairly advantage some and disadvantage others.**
3) **Greater awareness of the complexity of community health and health care, and the need for a systems approach to find enduring solutions to complicated problems.**
4) **A global pandemic revealed unequal infectious disease risks and outcomes. The pandemic also revealed unequal effects of treatment measures.**
5) **More awareness concerning the consequences of excluding communities from decisions and actions that directly affect them.**

Many cultural forces have impacted the importance and understanding of community engagement. This chapter presents information about how we, community engagement practitioners and partners, define community and many aspects of community engagement. It describes models and frameworks that have been transformational. While no chapter could review all available and relevant social science and public health literature about community and community engagement, this introduction highlights contributions from many disciplines. The development and practice of community engagement draws from sociology, political science, epidemiology, cultural anthropology, organizational development, psychology, social work, and other disciplines (Minkler & Wallerstein, 2008). The interdisciplinary background has helped to ground community engagement in values of fairness, social justice, collective impact, trustworthiness and listening (Wallerstein & Duran, 2006). In addition, the practice of effective, meaningful, and equitable community engagement is essential to developing partnerships. A diverse array of people and organizations can partner to influence health. Such partners include public health agencies, practice-based researchers (in clinics and health care delivery organizations), government agencies, non-governmental organizations, policymakers, community organizations, and community members.

Changes in Community Engagement

Major advances in the science and practice of community engagement have included:

1) **Newer and more dynamic models and concepts of community engagement**
2) **More advocacy and public commitment for community engagement**
3) **More scientific disciplines and sectors of society recognizing the importance of community engagement**
4) **A heightened emphasis on ethical and meaningful engagement with communities for sustainable changes**
5) **A greater awareness and growing evidence base that community engagement is essential to achieving social justice, environmental justice, and health equity**

In general, the goals of community engagement are to build trust, enlist new resources and allies, create better communication, shift power relationships, honor and mobilize different forms of knowledge, and improve overall health outcomes as successful projects evolve into lasting collaborations (Centers for Disease Control and Prevention, 1997; Wallerstein, et al., 2020, Frerichs et al., 2017; Eder et al., 2013).

The Rationale for Community Engagement: It's Essential to Public Health

The rationale for community-engaged health promotion, policymaking, and research is rooted in society's knowing that lifestyles, behaviors, and the incidence of illness are all dependent upon our social and physical environments (Hanson, 1988; Institute of Medicine, 1988). This "ecological" view is consistent with the idea that health inequities stem from socioeconomic conditions (U.S. Department of Health and Human Services, 2021) and that the multiple influences on health are best addressed through partnerships. The ecological view also aligns with the World Health Organization's (WHO) view of a social gradient for health and illness. In this gradient, the lower the socioeconomic position, the worse the health. WHO draws on numerous studies that suggest that social determinants of health account for 30-55% of health outcomes (World Health Organization, 2024).

A number of major national and federal initiatives reflect the growing commitment to community engagement, including:

1) **The Patient-Centered Outcomes Research Institute (PCORI), Clinical and Translational Science Awards Program (CTSA) from the National Center to Advance Translational Science of the National Institutes of Health (NIH-NCATS)**
2) **The Research Centers in Minority Institutions program of the NIH**
3) **CDC's Prevention Research Centers**
4) **The practice-based research networks of the Agency for Healthcare Research and Quality.**

The All of Us Research program (Denny et al., 2019; Mapes et al., 2020) is another program that understands the need to enlist the support of community engagement hubs across the country. They are working to include 1,000,000 or more diverse participants in biomedical research to provide all types of researchers secure access to a data set that represents the diversity of our nation.

Healthy People 2030, which details U.S. national health objectives, also emphasizes collaboration among diverse groups as a way to improve health. Similar commitments have been made at the international level, with the United Nations Global Preparedness Monitoring Board calling for "community-centered" approaches to preparedness and response to health emergencies (Bedford et al., 2019; International Federation of Red Cross and Red Crescent Societies and the International Committee of the Red Cross, 2022). While commitments to embedding community engagement into institutional structures are growing, the complexity and interconnectedness of the challenges we face point to a need for greater engagement of multiple sectors of society to build community capacity to solve problems.

Concepts of Community and Community Engagement

The literature contains no standard definition of community. However, commonly used definitions coalesce around a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographic locations or settings (MacQueen et al., 2001). While many people still think of community in terms of people in a geographic area, there is now more focus on a common identity shared by its members (Campbell & Jovchelovitch, 2000), as well as the notion that a single individual may belong simultaneously to many different communities—social, cultural, ethnic, vocational, spiritual, physical, intellectual, economic, etc. (Minkler & Wallerstein, 2004). Community as a social unit involves social networks, interaction, and interdependency. Communities are not monolithic, and often include unequal distributions of authority, access, and power over decision-making and resources (by gender, sociocultural background, physical and mental ability, ethnicity, language, and religion/faith) (UNICEF, 2019).

Communities are also not static. Community members do not all view their community with the same degree of affiliation and/or affinity. Individuals have their own sense of community membership and may have a sense of belonging to more than one community. An individual's affiliation with and/or identification with a community is complex and dynamic and affects their participation in community activities (Coomb et al., 2020). Researchers, community leaders, and community members may define community differently.

There are many definitions of community engagement from many different organizations. Each definition focuses on aspects of engagement that align with the organization's core values and mission. The first two editions of the *Principles of Community Engagement* defined community engagement as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people" (Centers for Disease Control and Prevention, n.d., p. 9).

The science and practice of community engagement has advanced over the past decades. Community engagement addresses concepts not explicitly addressed in the previous definition, such as trust, sustainability, equity, inclusion, and community-centeredness. In writing this third edition, the authors decided to create an updated definition of community engagement.

The lead editors and Chapter 1 authors reviewed 15 definitions of community engagement from different organizations. The organizations included the World Health Organization; Robert Wood Johnson Foundation; National Academy of Sciences, Engineering, and Medicine; Campus-Community Partnership; Carnegie Foundation; National Institutes of Health, and others. We filtered these definitions through our combined decades of experience building trusting, respectful relationships with our community partners. We developed and vetted a revised draft definition with community engagement leaders, practitioners, and co-authors of this edition of *Principles of Community Engagement*. This new definition incorporates changes in community engagement related to the emergence of digital and virtual communities, national organizations embracing community engagement, advances in scientific evidence, and feedback from community members. This updated and enhanced definition of community engagement is:

> *Community engagement builds sustainable relationships through trust and collaboration, strengthening 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.*

Community Engagement to Benefit Community Health

Culture and health are intimately connected. Both culture and health are shaped by social, physical, and economic environments. Community engagement processes enable tailoring of health-related programs to fit community contexts.

Problems are complex, so all parts of communities need to bring resources/assets and work together. Community engagement processes bring together many types of people and perspectives to improve the community. When participants build trusting and respectful relationships with each other, the relationships become a powerful asset to the community's vibrancy and resilience. Keys to sustainable relationships include commitment to:

1) **Sharing power (shared decision-making and shared consequences)**
2) **Sharing resources**
3) **Learning from others (humility)**
4) **Taking collaborative action**

A key to collaborative action is acting on real and relevant community needs in an inclusive and community-centric way.

In collaborative community-engaged research (CEnR), partners have recognized how community engagement can benefit communities and the people who participate in change processes (Baldwin et al., 2018; Hoekstra et al., 2020; Wallerstein & Duran, 2010). In other words, both the process and the outcome can strengthen the health of community members and build sustainable changes.

The Financial Perspectives of Community Engagement

The time commitment and resources required to engage community are substantial. Many funders and researchers still underestimate the amount of time and money it takes to develop and maintain enduring relationships beyond and between funded, time-limited projects. However, there are ethical costs of not engaging communities. The COVID-19 pandemic revealed the disproportionate loss of lives in minority, underserved, and marginalized communities. This disproportionate loss led many to push for policies that make community engagement essential and not optional (Grumbach et al., 2021).

Four academic institutions assessed barriers to fiscal requirements for essential community partnerships (Carter-Edwards et al., 2021). Difficulties included:

1) **Insufficient partnership equity**
2) **Sub-par communication strategies**
3) **Unclear institutional policies and procedures**
4) **Overwhelming fiscal processes**

The authors suggested improvements in all four areas to meet financial expectations. The financial aspects of community engagement need to be explored further in order to move the field forward. This study and others have identified that there are many other non-financial costs to all participants. Researchers experience personal challenges when working in a research partnership. Engaging in authentic power sharing over time involves additional time and effort. Partners report experiencing challenges when working in a research partnership. Challenges include feelings of not being listened to, not being taken seriously, being frustrated and/or dissatisfied about the research processes and feeling overburdened by tasks and responsibilities. Community partners have reported that research partnerships may create challenging demands on them, which further marginalizes the group.

Community Engagement has Many Approaches that Fit Different Purposes and Contexts

The past decade has seen expanded application of "tried and true" approaches of community engagement as well as new approaches. The new approaches come from many perspectives including from virtual, systems, humanitarian, social justice, citizen science, and data science (Cottler et al., 2013; Cottler and Nagaranjan, 2012; King et al., 2016; Keller et al., 2017). In addition, a broader array of scientific disciplines (for example, genomics and informatics), along with public, private, and philanthropic sector entities, have begun to initiate community-centered engagement processes.

Individuals are relying more on **virtual perspectives**, or social media, to access information, meet people, and make other decisions that affect their lives. Computer-mediated forms of communication are abundant. They include email, text messaging, e-chat rooms, Facebook, Instagram, TikTok, YouTube, X (formerly Twitter), and other face-to-face web-based platforms, such as Zoom, GoogleMeet, and WebEx (Fedorowicz et al, 2020; Day et al., 2021). Many of these platforms are used by social groups and groups with a common interest who create "virtual communities" via their interaction on the Internet (Rheingold, 2000). Without question, these virtual communities are potential partners for community-engaged health promotion and research. Many community engagement initiatives have a social media presence to engage specific populations with a shared interest. Successful approaches often engage many community leaders, including community members unaffiliated with a particular agency or social network.

From a **systems perspective**, we understand that while all sectors can substantially affect health, most have a primary focus other than health. Schools focus on education. The transportation sector focuses on moving people and products. Economic entities focus on enterprise and employment. Faith-based organizations focus on spiritual wellbeing (Zurcher et al, 2018). For example, while education is an independent predictor of health, we know that schools also have direct effects on health. For example, many schools provide assets such as regular, nutritious meals, medical care, clothes washing facilities, and food pantries. Education itself impacts health through employment opportunities, income, wealth, health insurance, and other benefits that impact health over the course of a lifetime. The transportation sector either enables or hinders access to medical care, parks, green spaces, shopping, and cultural and social experiences that can

A community resident trained in lead paint abatement.
Lloyd DeGrane, 2018.

foster community cohesion. Urban planning, the design of public space, and the density of communities can affect health and wellness. Another powerful example is the expanded role that libraries play in health. They are a trusted source of health information for the community while also reaching out to meet community needs at various levels. All of these entities meet the community where they are and as such, all sectors have an important role to play in the health of communities. Addressing a community's complex problems requires integration, collaboration, and coordination of resources from all sectors. From a systems perspective, collaboration is thus a logical approach to positive and successful outcomes (Kaplan et al, 2016).

The **humanitarian response perspective**, led by UNICEF, has developed minimum quality standards and indicators for community engagement (UNICEF, 2019). Hoekstra and colleagues (2020) identified overarching principles, strategies, and outcomes/impacts from reviewing more than 80 published reviews of research partnership studies. Such et al. (2022) confirmed a common need for "structural and relational components" involving (Such et al., 2022):

1) **Shared power**
2) **Relational trust**
3) **A common language and understanding**
4) **Adequate resources**
5) **Leadership that champions collaboration**
6) **Identification of "win-win" strategies**
7) **Building capacity through training and knowledge sharing**
8) **Meaningful community engagement**

Grumbach et al. (2021) and multiple researchers involved in translational science stated that COVID-19 exposed how community leaders were not engaged early in the research process (Grumbach et al., 2021). The authors are community engagement leaders who spoke on behalf of Partners for the Advancement of Community Engaged Research (PACER). The PACER researcher at 40 U.S. institutions recommended that their institutions do the following (Grumbach et al., 2021):

1) **Immediately develop and implement a plan to achieve great diversity among the research workforces**
2) **Modify human research review board protocols to require a community engagement plan**
3) **Require a course in community engagement to facilitate better, and more authentic, community engagement**
4) **Establish a community advisory board for any institution receiving federal funding**

The PACER researchers also recommended that funding agencies require funding applications to have a section describing plans for community engagement. They should also include partners in the review of funding applications and increase investment in community engaged research.

What is clear from the variety of approaches that were examined and described is that there is not a "one-size-fits-all" approach to community engagement (Renmans & Castellano Pleguezuelo, 2023). This is because contexts, mechanisms, and outcome expectations vary. Contexts focus on who, what, and where. Mechanisms focus on how and when. Outcome expectations focus on why and for what purpose. The literature contains many descriptions of community engagement principles, practices, purposes, impacts, and outcomes. This chapter sets the stage for the development of indicators that could increase robust evaluation of community engagement. Stallings et al. (2019) developed the "community stakeholder impact on research taxonomy" that offers common reporting standards and measures that could advance the science and practice of community engagement. These, along with future evaluations, could offer more practical and precise guidance about approaches that work best in different contexts and for achieving different outcomes.

Important Concepts for Community Engagement

The social science and public health fields provide useful definitions of community and concepts that are relevant to the practice of community engagement. We share some of the most important concepts below.

Development of Partnerships. In 1997, the *Principles of Community Engagement* described four community engagement relationship elements:

1) **Know the community, its constituents, and its capabilities.**
2) **Establish positions and strategies that guide interactions with constituents.**
3) **Build and sustain formal and informal networks to maintain relationships, communicate messages, and leverage resources.**
4) **Mobilize communities and constituencies for decision-making and social action.**

Participation. Community engagement requires participation of community members in projects that address their concerns. Meaningful community participation means that all participants share in generating ideas, making decisions, taking responsibility, and sharing power. People are motivated to participate when they feel heard, take action to address injustice, and contribute to the health and well-being of their community.

Without mutual respect and shared leadership, partnerships cannot build trust, develop resources, or be effective (Griffith et al., 2020, 2021; Minkler & Wallerstein, 2008; Wilkins et al., 2021; Dave et al., 2018). However, with participation comes an understanding that a community member's time is valuable and limited. Given the expanded roles that community members are often asked to play, the agency or academic group should meet with the community partner to determine appropriate methods and compensation (Minkler & Wakimoto, 2021).

Social Justice. Social justice has been defined as the "full and equal participation of all groups in a society, mutually shaped to meet their needs. Social justice includes the fair and even distribution of resources" (Bell, 2016; Ruijsbroek et al., 2017). The outcomes are shared equally and provided to all members with the end products benefiting all (Stronks et al, 2016; 2020).

Applying these fundamental perspectives to community engagement is key for promoting health equity. Striving for principled action that includes seeking justice is also imperative so that no one is left behind (Gilmore-Bykovksyi et al., 2021). Researchers and practitioners using community engagement approaches to social justice are aware that inequities persist as a result of policies and practices. These policies and practices create an unequal sharing of money, power, and resources among communities based on race, ethnicity, class, gender, place, and other factors.

Culture. Communities are not homogeneous. Communities consist of diverse groups with different histories, social structures, value systems, and cultural understandings of the world. Culture shapes identities and fosters notions of a "sense of community" (Mannarini et al., 2022). Culture organizes the relations and interactions among individuals and groups, how meaning is communicated, and how power is defined. Culture shapes ideas about partnership, trust, negotiation, collaboration, and the process of community engagement (Carter-Edwards et al., 2021; Graham et al., 2016; Silka et al., 2008). Anthropologist Mason et al. (2020) said that "culture captures the patterned ways in which individual lives unfold in multilayered, dynamic group contexts. Cultural groups are internally diverse, and group boundaries are continually negotiated in response to internal and external challenges. Culture creates numerous intersections for individuals: people belong to multiple groups at once, and those groups interact within continuously evolving social, economic, political, and environmental contexts" (Mason et al., 2020, p. 477).

To achieve successful collaboration, all should critically reflect on their own culture and how it shapes their beliefs (Wallerstein et al, 2019; Airhihenbuwa, 2007; Minkler, 2004; Meissner et al., 2020; Wallerstein et al., 2020). For example, attention to language suggests that researchers should refrain from labeling communities as "at risk," or "difficult to recruit" or "hard to reach." Very often the communities are not "hard to reach" or "difficult to recruit." They are right there in the community. It is up to researchers to meet them where they are, with socially acceptable methods and timetables. Showing up in a community when a grant deadline is looming and expecting them to participate is one example of how researchers may feel the community is "difficult to work with." In reality, the fault lies with the researcher for bringing the community in too late in the process and trying to work quickly against a deadline.

Another example is the colonization and historical trauma that happened when the majority population did not understand or respect Indigenous (Native American) culture. The result was unjust social and economic hardships to Native Americans. A commitment to understanding culture within community engagement and interacting with humility, requires engagement with other perspectives (Figure 1.1). For example, the First Nations Health Authority and Aboriginal Peoples in British Columbia put forth the role of culture in the "Creating a Climate of Change" (First Nations Health Authority, n.d.).

Figure 1.1 Cultural Reflection on Humility and Safety

Cultural humility *is a lifelong process of reflection to understand individual and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust.*

Cultural safety *is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It is the outcome of people feeling safe when receiving health care services. Health care providers must understand, uphold, and practice cultural safety at all levels of the health system, including governance, within health profession regulatory bodies and within professional practice.*

Source: (First Nations Health Authority, n.d.) *Creating a Climate for Change: Cultural Safety and Humility in Health Services Delivery for First Nations and Aboriginal Peoples in British Columbia*. https://www.fnha.ca/Documents/FNHA-Creating-a-Climate-For-Change-Cultural-Humility-Resource-Booklet.pdf

Partnerships and Cross-Sector Collaborations. Cross-sector collaboration is needed to address root causes of persistent public health challenges. Coalitions, councils, committees, advisory boards, collaboratives, networks, and alliances are approaches to bringing diverse people and organizations together for a common purpose. Calancie and colleagues (2021) conducted a systematic literature review to identify studies describing theories, models, frameworks, and principles for cross-sector collaboration. Their synthesis of 95 studies revealed seven domains of community context:

1) **Group composition**
2) **Structure and internal processes**
3) **Group dynamics**
4) **Social capital**
5) **Activities that influence or take place in the community**
6) **Activities that influence or take place both within the community and collaboration**
7) **Activities that influence or take place within the collaboration**

The authors discussed community engagement strategies employed by collaborations and challenged researchers to use systems science methods to advance the effectiveness of cross-sector collaborations. Such et al. (2022) applied systems thinking to understanding pathways that underpin successful collaborative governance in the dynamic context of policy development and implementation. Their "causal loop diagram" depicts pathways that can support or undermine the legitimacy and credibility of collaborations (Such et al., 2022). Similarly, Gawerc (2021) identified five coalition processes and practices that cultivate solidarity across difference and inequality. These processes and practices include those listed below (Gawerc, 2021).

1) **Uniting around shared principles while engaging and recognizing differences**
2) **Acknowledging and managing inequalities**
3) **Making space for each other**
4) **Attending to and managing conflict**
5) **Performing actions that confirm the shared commitments and negotiated identity**

Community Organizing. Community organizing provides insights and models for communities to come together to work for change. Community organizing is a process by which communities identify their assets and concerns, prioritize and select issues, and develop and implement action strategies for change (Minkler et al, 2021). The main feature of this process is the voice of the community (Oh et al., 2021).

Capacity-Building. Building capacity to improve health involves the development of sustainable skills, resources, and organizational structures. For engagement efforts to be fair, effective, and sustainable, all involved must be ready for collaboration and leadership. Building capacity also includes fostering shared knowledge, leadership skills, and an ability to represent the interests of one's constituents. Partners must conduct capacity building with an understanding of the specific environment (e.g., social political, economic) in which it will take place (Broussard et al., 2020; Collie-Akers et al., 2021; Israel et al., 2019; Ofili et al., 2019). Capacity-building is an integral part of community engagement efforts for challenging power imbalances and effectively addressing problems.

Ethics. Even with successful partnerships, community engaged research must recognize limits to its actions. An accepted ethical research code in the United States already exists. A regulatory process based on this code has been developed for all federally funded research that involves people. Historical failures to obtain voluntary and informed consent, and to avoid harm by mistreating rather than protecting individuals, led to an ethical code initiated to limit "human subject abuses in biomedical research" (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research,1979).

Numerous boards and committees at institutions across the world provide ethical review of research involving humans, often referred to as "human subjects research." While institutional review boards and ethics review committees in the United States must base their decisions on Department of Health and Human Services guidance, variation exists in how institutions and individuals interpret ethical principles. There continue to be challenges in the ethical oversight of how science produces and uses knowledge.

Research that involves people is divided by classification of risk. Studies can be minimal and greater than minimal risk to participants. Minimal risk studies approximate the harms an individual will likely encounter in daily life. Greater than minimal risk involves activities that increase exposure to potential harm (Revised Common Rule 45 CFR [Code of Federal Regulations] 46102(h)(i)). The federal government has a policy to protect people in research and assess the research risk level. The policy is the Federal Policy for the Protection of Human Subjects, or "Common Rule." The Common Rule ensures that all aspects of a research study, such as informed consent and assurances of participants' confidentiality, are protective of the people who participate in the study as "research subjects." (U.S. Department of Health and Human Services, 2024).

In light of an increase in community-engaged research (CEnR) projects, review committee members have a heightened awareness of the need to better understand the implementation of these projects in the community (Ross et al., 2010; Anderson et al., 2012). Many institutions have developed their own curriculum to explain community engaged research to their staff (Jetter et al., 2015). Institutional Review Boards (IRBs) must appreciate and assess the ethical issues of research conducted within a community or with community partners (Malone et al., 2006; Bromley et al., 2015).

In fact, at an increasing number of institutions, community members are required to be on review committees when CEnR projects are reviewed. Various training curricula are utilized across institutions to support this requirement (Anderson, 2015; Yonas et al., 2016). Community members have also engaged in discussions about research ethics through deliberative democracy, community advisory boards, community engagement studio input, and through other processes (del Campo et al., 2013; Shore et al., 2015). Person-centeredness in medicine encourages improvement in the ethical review of community engaged research (Rosenthal et al., 2009; del Campo et al., 2013; Blumenthal, 2006; Neufeld et al., 2019).

While the value of CEnR is now well-established, opportunities for improving community member engagement in applying ethical principles to CEnR project reviews often continue to be missed (Flicker et al., 2007). Implementation of recent revisions to the Common Rule, particularly the emphasis on creating more understandable informed consent forms, could also benefit from community input.

The goal of connecting research more directly to clinical practice depends upon the institutional success at engaging diverse communities in all aspects of the research enterprise. The National Center for Advancing Translational Sciences (NCATS) Clinical and Translational Science Award program of the National Institutes of Health and the Patient Centered Outcomes Research Institute (PCORI) both advance these goals. Both NCATS and PCORI can provide methods and tools for increasing research engagement with community and patient voices and perspectives and for including those voices and perspectives in the ethical review of both clinical and community-engaged research.

We acknowledge that as both the volume and scope of CEnR projects expand, continued improvement with both the ethical review and conduct of research will continue to depend on our ability to apply the principles of community engagement.

Selected Theoretical Frameworks and Models for Community Engagement

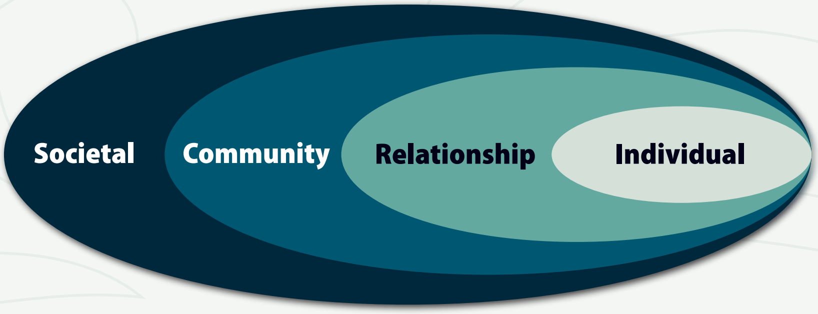
Since the 2nd edition of the *Principles of Community Engagement*, there has been a welcome increase in theories, models, and frameworks on community engagement. The process of developing and using a theory, model, or framework means that people are thinking; talking; considering activities, outputs, and their intended effects; exploring the relationships between them; observing and documenting phenomena; testing assumptions; and developing hypotheses. A theory, model, or framework can help people navigate through or stay oriented amid life's many responsibilities. These tools can help people bring about change, show change has happened, and describe how change happened. The literature describes many stories of how communities (geographic, scientific discipline, occupational field, etc.) have used a model, revised a model, or created a new model to initiate, incorporate, or integrate community engagement into their work. CTSA researchers developed a logic model for community engagement to help with measuring model components including important relational aspects of community-academic initiatives, with the aim of "better science, better answers, better population health" (Eder et al., 2013, p. 1430).

We have selected some models or conceptual frameworks that have extensive evidence of their use and a newer model that focuses on achieving health equity through community engagement.

1) **Theory of Collective Action.** The beauty of simple things is that they are timeless and withstand any social or scholarly examination. Such is the case with the Theory of Collective Action (Olson 1965). It serves as a theoretical framework for analyzing participation and is a resource for evaluating community engagement. Furthermore, its tenets provide a framework for evaluating social dilemmas in a collective manner through the lens of community engagement. Olson's work has also been important when aggregating the voices of people who have historically been disadvantaged and disempowered by acknowledging that a collective voices is required for advancing a position. Voices speaking in unison have bolstered groups to be heard in areas such as policy and programs where they may otherwise be overlooked (Prentice et al., 2020).
2) **The Social-Ecological Model (SEM) of Health.** The Social-Ecological Model describes health as an outcome affected by the interaction among the individual; the group/community; and the physical, social, and political environments (McLeroy et al., 1988). The Social-Ecological Model is recognized as a classic in the field. It is often used to identify factors that contribute to poor health and to develop approaches to disease prevention and health promotion. As shown in Figure 1.2, the first level of the SEM includes individual biology and other personal characteristics, such as age, education, income, and health history. The second level, relationship, includes a person's closest social circle, such as friends, partners, and family members, all of whom influence a person's behavior and experiences. The third level, community, explores the settings in which people have social relationships, such as schools, workplaces, neighborhoods, and zip codes and identifies characteristics of these that affect health. Finally, the fourth level evaluates broad societal factors, such as policy decisions, regulations, and requirements that either promote or deter health behaviors (Centers for Disease Control and Prevention, 2007; Krug & Dahlberg, 2002). For example, the policy of mandatory calorie labeling on food that encourages more informed dietary choices promotes health behaviors.

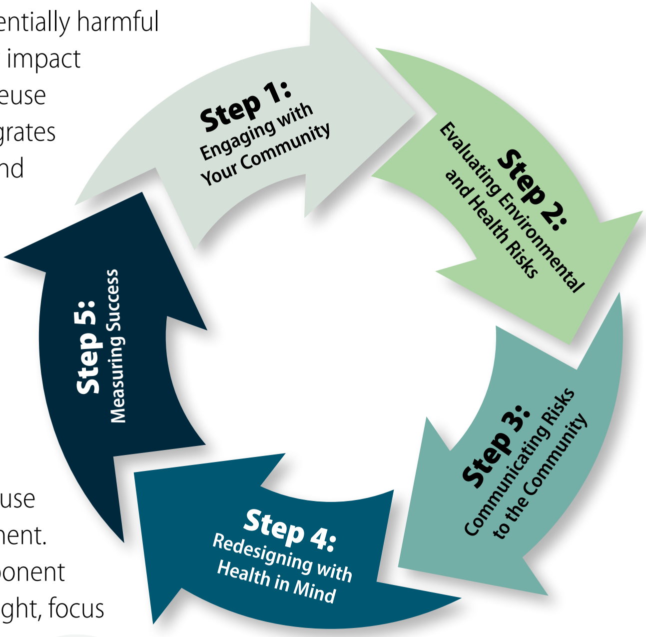
Figure 1.2 The CDC Social-Ecological Model: A Framework for Prevention (Bronfenbrenner, 1977).

Public health professionals and academic researchers often use this framework to understand the drivers of behavior and to develop actions (called interventions) at each of the four levels in order to influence a health outcome. For example, an effort to reduce childhood obesity (Cory et al., 2021) might include the following activities at the four levels of interest:



- **Individual:** Conduct education programs to help people integrate healthy food choices, increase their physical activity, and control their weight.
- **Relationship:** Create walking clubs to promote exercise; promote community gardening groups.
- **Community:** Work with local stores (i.e., grocery and convenience) to increase access to fresh fruits and vegetables. Establish farmer's markets that accept food stamps. Identify walking trails, parks, and indoor exercise sites. Work with local employers to develop healthier onsite food choices.
- **Society:** Support policies that eliminate soft drinks and high-calorie snacks from schools. Work to include bike lanes or other supports for active transportation in road maintenance budgets.

3) **ATSDR's 5-step Land Reuse Model: Community Engagement in Practice.** The Agency for Toxic Substances and Disease Registry (ATSDR) focuses on environmental contamination and ways to reduce potentially harmful chemical and hazardous exposures that can negatively impact community health outcomes. ATSDR's National Land Reuse Health Program incorporates a simple model that integrates community engagement throughout the process of land reuse and community revitalization. While the 5-step Land Reuse Model focuses on the redevelopment of contaminated properties, it is adaptable to a wide range of community projects. For example, the model can address improving the built environment, social and environmental justice concerns, and community-engaged research. The 5-step Land Reuse Model promotes "Healthfields"—community revitalization that aims to improve health. The 5-step Land Reuse Model is a cycle that begins with community engagement. However, community engagement is an integral component of all five steps. The steps of the model, shown to the right, focus on community revitalization.



Step 1: Engaging with Your Community

Engaging partners is a key element of land reuse and redevelopment and overall community revitalization. When people work together, they can create a well-rounded and holistic approach to building a better community.

Step 2: Evaluating Environmental and Health Risks

Engaging the community to learn about their environmental and health concerns from the beginning stages of community revitalization planning can reveal opportunities to promote a healthier community. Environmental and public health professionals play a strong role at this stage of the cycle. They are learning from the expertise of community members, who may know about historic sites that may have left contamination behind. They also are applying their technical skills to evaluate potential environmental and health risks of these sites.

Step 3: Communicating Risks to the Community

Technical experts and community members work together to build shared meaning about health risks. They make informed decisions about actions that can be taken to address both risks and risk perceptions. These decisions can result in collaborative action. This process involves an on-going exchange of information, opinion and advice between technical experts and community members. For example, technical experts may share information about risks of contaminants or hazards associated with an old industrial site or blighted/abandoned buildings. Community members may mobilize to address any environmental and health issues related to these sites or buildings.

Step 4: Redesigning with Health in Mind

To be a part of redesigning a community with health in mind requires community engagement and an overall community-driven revitalization plan. It is important to ask questions to build a healthier community, such as what are the health benefits of a revitalization approach?

Step 5: Measuring Success: Environmental and Health Change

Through community engagement, communities are creating their own indicators to measure changes in their environment or health over the course of revitalization projects. There are many ways to measure success. Some examples of indicators include:

- Number of grocery stores
- Maps of sites with known contamination that are close to residential properties
- Before and after revitalization surveys
- Crime rates
- Number of healthcare facilities
- Community-defined ways to measure changes in environmental and health outcomes

The 5-step Land Reuse Model is adaptable to a specific community project, such as "The 5-step Model to Achieve Healthy Schools," with each step tailored to the goals of a project. For example, Step 2, Evaluating Environmental and Health Risks, may be important in achieving healthy schools specific to indoor air quality and the type of chemicals used to clean the schools. The model could be adapted to evaluate health risks related to lack of physical education programs, or to evaluate health impacts of the school lunch program.

ATSDR encourages communities to use the 5-step Land Reuse Model to integrate and maintain community engagement, putting the community first at each step of the process.

4) **Diffusion of Innovation.** Everett Rogers (1995) defined diffusion as "the process by which an innovation is communicated through certain channels over time among the members of a social system." The first stage, knowledge, exposes the individual to an innovation but lacks information about it. The second stage, persuasion, actively seeks innovation. In the decision, or the third stage, the individual weighs the advantages and disadvantages of the innovation and whether to adopt or reject it. If adoption occurs, the individual moves to the fourth stage, implementation. In the fifth stage, confirmation, the individual decides whether to continue using the innovation and to what extent. Individuals at each stage are described as innovators, early adopters, the early majority (who deliberate longer than early adopters and then act), late adopters, or "laggards" (who resist change). This framework is used for many different behaviors. Adoption is based on the relevance of the strategy, its compatibility with norms and beliefs, how complex it is to adopt, how feasible it is, and how people observe its results.

   A community-engaged health promotion campaign might include raising awareness about the severity of a health problem (knowledge), transforming awareness into concern for the problem (persuasion), establishing a community-wide intervention initiative (adoption), developing the necessary infrastructure to reach residents (implementation), and evaluation of the project (confirmation). This framework was adapted for dissemination and implementation science efforts (Brownson et al., 2018; 2021). Chapter 9 explains these efforts in more detail.

5) **Community-Based Participatory Research (CBPR).** The community-based participatory research (CBPR) model is perhaps one of the most well-known frameworks under the umbrella of community-engaged research (CEnR). The model has recently been updated (Wallerstein et al., 2020; Cacari-Stone et al., 2014; Hohl et al., 2022). CBPR involves establishing an equal partnership between researchers and community partners across all phases of research: design, setting priorities, implementation, interpretation, dissemination, and application of findings. The partnership generates practical solutions while building balanced relationships with the community. The model's author describes the revised model in Chapter 8.

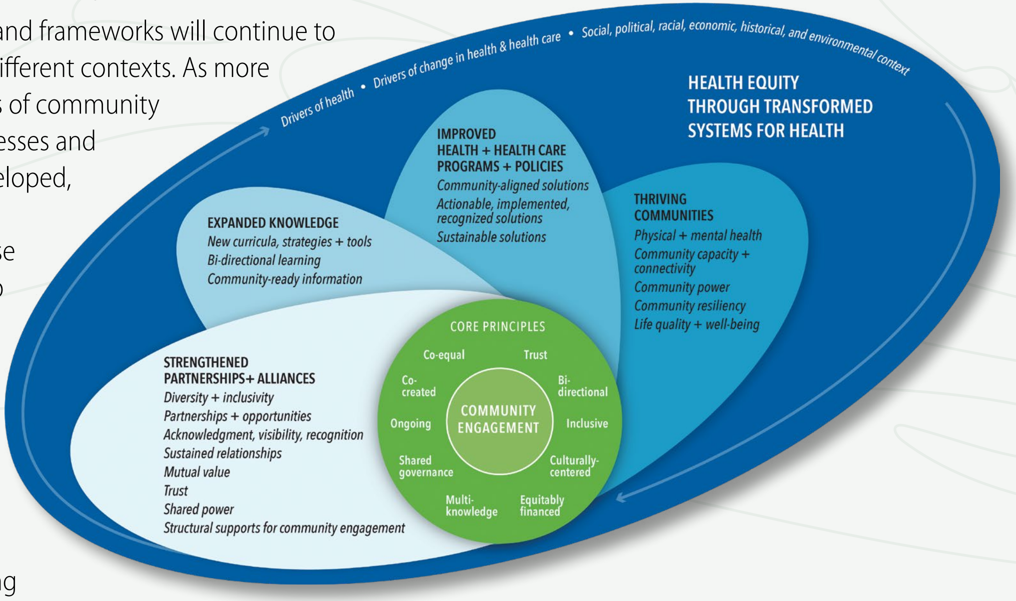
6) **Engagement Model to Achieve Health Equity.** In 2022, the National Academies of Sciences Engineering and Medicine released the Assessing Meaningful Community Engagement Conceptual Model (Aguilar-Gaxiola et al., 2022). The model uses the CDC definition of community engagement but calls for it to be more "meaningful" and more directed at addressing health inequities. Meaningful engagement requires decision-makers to defer to communities and share power for equitable transformation. It is important to note that meaningful community engagement requires working closely with communities to understand their preferences on how, when, and to what level and degree they want to engage in efforts. Figure 1.3 offers a visual illustration of core principles of community engagement. This includes a foundation of trust, bidirectional influence and information flow, being inclusive, being culturally centered, being equitably financed, having multi-knowledge, sharing governance, having ongoing authentic and enduring relationships, co-creating, and having co-equal partners. The conceptual model has four broad domains of measurable outcomes:

   1) **Strengthened partnerships and alliances**
   2) **Expanded knowledge**
   3) **Improved health and health care programs and policies**
   4) **Thriving communities**

Under each domain are potential and relevant indicators. The conceptual model presents 19 mutually exclusive indicators divided across the four domains. Each indicator is, in turn, associated with specific measures that are supported by results and used to assess if the engagement taking place is meaningful.

Figure 1.3

A Conceptual Model to Advance Health Equity through Transformed Systems for Health, used with permission from the National Academies of Medicine (Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies, 2022).



Theories, models, and frameworks will continue to be used in many different contexts. As more standard measures of community engagement processes and outcomes are developed, more insights will likely emerge. These insights could help practitioners select the best model for use in different contexts or help them diagnose processes that may not be working well so that they can make improvements. The best models are the ones that are used by participants to meet their needs within their context. Chapter 3 provides examples of how these models are used in the field.

Reflections on Community Engagement and the COVID-19 Pandemic

Given the experience with the COVID-19 pandemic, it is important in this opening chapter to reflect on how that experience has focused attention on social justice and health equity. This third edition of *Principles of Community Engagement* is timely as a reminder of what can happen when we fail to engage communities.

For outbreaks of new infectious diseases, community support for and participation in practices and/or policies that reduce the spread of disease is essential. COVID-19 showed that there are many different drivers for and against performing recommended protective behaviors and receiving recommended treatment (Petherick et al., 2021). As a result of the pandemic's impact, numerous professional disciplines and organizations have publicly declared community engagement an essential part of their work. For example, public health has made community engagement a part of its accreditation standards and integrated it into the 10 essential public health services. The Association of American Medical Colleges has developed a community engagement toolkit in collaboration with its members. They have also established 10 principles of trustworthiness (Association of American Medical Colleges Center for Health Justice, n.d.). The American Medical Association has created a new Center for Health Equity to transform ideas into actions.

Several groups also produced public messaging and calls to action. One group, PACER (Partners for the Advancement of Community Engaged Research) of the Association for Clinical and Translational Science, produced a compendium of community engagement responses to COVID, sharing valued approaches each team had undertaken to "*not* turn its back on the community during the pandemic lock-down" (Eder et al., 2021; Michener et al., 2020). Some examples of these approaches were:

1) **Listening sessions and collection of data for use by local and state officials to dispel myths**
2) **Working with city and county departments of health**
3) **Conducting virtual national town hall meetings (Our Community Our Health) to share stories and findings**
4) **Engaging underrepresented populations in research**

During the pandemic, these actions helped demonstrate trustworthiness.

The field is also asking for academic medicine to embrace community collaboration as its fourth mission (Alberti et al., 2021). Community collaboration would be a major advance for schools of medicine that have primarily focused on clinical service, teaching, and research. In addition, there has been a renewed effort to develop a curriculum in community engagement for the training of various professionals. The WHO has developed a community engagement training package (Bayugo et al., 2022) . The Urban Institute also created a guide for community engagement during the pandemic (Fedorowicz et al., 2020).

In public health, community engagement should generally be a part of every person's job. However, organizations that want to effectively engage communities need staff members who have special expertise to facilitate and lead productive community engagement processes. These specialists must have expertise in listening, group facilitation, and both qualitative and quantitative research capabilities. Effective community engagement requires leadership support, as well as organizational processes and resources that sustain ongoing community involvement (Carter-Edwards et al., 2021).

Chapter Conclusion

The past decade has seen much progress in the adoption, application, innovation, and evaluation of the practice and science of community engagement in many sectors of society and across many scientific disciplines. However, work is still needed to fully integrate community engagement into organizational processes. It will require a trained workforce with adequate resources and support for effective community participation that is coordinated, sustained, and prioritized for research and evaluation.

The complex challenges faced today cannot be solved without engaging communities. Addressing health inequities and social determinants of health, including systemic racism, will depend upon ongoing "necessary conversations" that are essential for effective community engagement (Plough, 2022). Since the COVID-19 pandemic, organizations all over the world realize the importance of hearing everyone's voice. There is growing momentum for engaging communities to improve the things that make a community healthy (Community Commons, n.d.). The time is ripe to recommit to apply what was learned over the years, especially during the pandemic, and begin another decade of major advances in meaningful, inclusive, and diverse participation in the social change processes that lead to improvements in the health and well-being of people across the globe. The next years should be devoted to advancing the science of community engagement and measuring the impact our efforts will have on population health.

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Appendix 1: Accessible Descriptions for Complex Graphics

Figure 1.3—A Conceptual Model to Advance Health Equity through Transformed Systems for Health

Figure 1.3 focuses on the core principles of community engagement, which intersect 4 domains of measurable outcomes. Health equity through transformed systems for health includes broad drivers of health; drivers of change in health and healthcare; and social, political, racial, economic, historical, and environmental context.

Website: https://nam.edu/wp-content/uploads/2022/03/Model-updated-12.11.21-Recovered.png

The core principles of community engagement are:

- Trust
- Bi-directional
- Inclusive
- Culturally-centered
- Equitably financed
- Multi-knowledge
- Shared governance
- Ongoing
- Co-created
- Co-equal

The 4 domains of measurable outcomes include

- **Domain 1—Strengthened partnerships plus alliances, including**
    - Diversity + inclusivity
    - Partnerships + opportunities
    - Acknowledgment, visibility, recognition
    - Sustained relationships
    - Mutual value
    - Trust
    - Shared power
- **Domain 2—Expanded knowledge, which includes**
    - New curricula
    - Strategies + tools
    - Bi-directional learning
    - Community-ready information
- **Domain 3—improved health and health care programs and policies, including**
    - Community-aligned solutions
    - Actionable, implemented, recognized solutions
    - Sustainable solutions
- **Domain 4—thriving communities, which includes**
    - Physical + mental health
    - Community capacity + connectivity
    - Community power
    - Community resiliency
    - Life quality + well-being

◀ *Return to Figure 1.3*

CHAPTER 2: PRINCIPLES OF COMMUNITY ENGAGEMENT

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Community engagement efforts are complex, challenging, and labor-intensive. Successful community engagement practices also require a unique skill set that even experienced leaders may not have previously developed. To provide a comprehensive approach to community engagement, engagement leaders organize actions and considerations into principles. Community engagement leaders who contributed to the two previous editions of *Principles of Community Engagement* concentrated on nine principles. This edition contains a tenth principle that recognizes "trustworthiness" as essential in establishing effective partnerships to advance health in communities. The following four sections emphasize the 10 principles and actions required to implement them:

- How to begin community engagement work
- What is necessary for engagement to occur
- How engagement can be successful
- What is necessary to sustain community engagement efforts

Each principle covers a broad practice area of engagement, often addressing multiple issues.

How to Begin Community Engagement Work

Principle 1. Be clear about the purposes or goals of the engagement effort and the populations and/or communities you want to engage.

One of the most important phases of building strong relationships with communities is pairing the communities' priorities with the engagement effort's activities, purposes, and goals. Members of a community connect with shared strengths or traits unique to their community. Partners must learn, identify, and adopt the community's purpose. This process may be informal at first and over time may shift toward some form of goal-setting exercises; it may be ongoing for years. In defining common ground, engagement leaders should promote open dialogue and foster collaborative relationships that help the partners become a part of the community. This places all parties at the center of the project while also centering the priorities of the community (Lichtenfeld et al., 2019).

The motivation for specific engagement efforts varies. Engagement leaders may see community organizing and mobilization as part of their mission or profession. In addition, they may recognize the strengths of community engagement to:

1) **Enhance the ethical foundations of action**
2) **Identify the issues**
3) **Design and deliver the programs or research**
4) **Sustain the outcomes**

Grantmaking agencies, legislation, or policy may make community involvement a condition of funding. Alternatively, outside pressures may demand that an entity be more responsive to community concerns.

Just as the impetus for community engagement varies, so do its goals. Efforts in community engagement could focus on specific health issues. In the COVID-19 pandemic, efforts focused on testing, awareness, and then vaccine delivery. Alternatively, efforts could have a broad focus, as in the following examples:

- Focus on overall community improvement. This includes factors such as economic and infrastructure development to promote health improvements and disease prevention.
- Assess community needs and assets to identify health-related or environmental concerns and areas that need action.
- Ask community members to become involved in planning, designing, implementing, and evaluating appropriate programs.

The focus level of goals has implications for managing and sustaining the engagement. A broader goal may enable community leaders to involve larger segments of the community. A narrower focus may keep activities more directed and manageable.

Community participation could have several dimensions. Leaders of community engagement efforts need to be clear about whether they are anticipated (Kudva & Driskell, 2009):

- Seeking data, such as health information
- Seeking information, advice, and feedback to help them design programs
- Looking to partner and share control with the community

The last bullet, above, includes being willing to address the issues that the community identifies as important, even if those are not the ones originally anticipated.

It is important to be clear about the community that partners are engaging—at the start of the engagement. Is it all those who reside within certain geographic boundaries? Is it a specific racial or ethnic group, an income-specific population, or an age group, such as youth? Is it a specific set of institutions and groups, such as faith communities, schools, or the judicial system? Is it a "virtual" community sharing a common interest? Or is it a combination? How might other collaborations or partnerships in the community of interest enhance engagement efforts? Answers to these questions will help establish the parameters for the engagement effort.

Principle 2. Become knowledgeable about the community's culture, economic conditions, social networks, political and power structures, norms and values, demographic trends, history, and experiences with efforts by outside groups. Be aware of each other's perceptions of past engagement activities.

Those wishing to engage the community need to be able to communicate why participation is worthwhile. Collaborate to establish clarity about the value of the work at the outset.

Prepare for a variety of responses from the community. The community responses may stem from past knowledge of or experiences with researchers, medical/public health professionals, related institutions, or local leaders. Consider views of the organization from the outside looking in. Community members often see large institutions as a whole. Community members may not differentiate between clinical services offered by a medical center and research activities conducted there. If they had positive or negative experiences with clinical care at a medical center, their perceptions of those experiences will transfer to the partnership and research experience. In fact, the treatment they receive as a patient or visitor in the medical center may affect their willingness to partner in the community. For example, if an academic medical center does not accept a community member's insurance, that would be a significant barrier to willingness to partner.

"Road-signs" along the way that could indicate a desirable or difficult partnership include the community's perceptions of several factors. These include feeling respected, long waiting lines, having their bags searched to visit a patient in the medical center, and accessing services only in English or in a language of their choice.

In the past, institutions (especially academic institutions) have gentrified communities, enacted eminent domain property seizures, and possessed parks and buildings that previously housed local businesses and public or low-cost housing. To foster community healing, institutions must acknowledge this history, consider and make possible reparations, and restore trust and transparency.

There may be many barriers when engaging a community that has been historically underserved. It is essential to recognize the complexity of community participation as an ongoing, evolving process of multidirectional communication. Aligning healthy community outcomes recognizes both the complexity of relationships and the importance of community participation in decision-making and solutions. The processes for community participation must be appropriate for meeting the overall goals and objectives of achieving and tailoring engagement practices.

One common misstep is oversimplifying or homogenizing communities. The term "community" may disregard the internal complexity in community perspectives, views, or socioeconomic status. Viewing *community* as a single entity with one position on an initiative can result in the mistaken impression that all people from that group share a perspective. The perspectives of subgroups may be overlooked, excluded, or marginalized. In addition, it is necessary to recognize that social justice issues may vary within communities. An imbalance in outcomes can cause resentment and diminishing support from one or all entities (Lichtenfeld et al., 2019).

It is important to learn as much about the community as possible, using different methods such as qualitative and quantitative approaches, and surveying as many community sources as exist. Many organizing concepts, models, and frameworks presented in Chapter 1 support this principle. Social-ecological theories, for example, emphasize the need to understand the larger physical and social or cultural environment and its interaction with individual health behaviors. Understanding how the community perceives the benefits and costs of participating will help decision-making and consensus-building and will translate into improved program planning, design, policy development, organization, and advocacy. Understanding the community will help in mapping community assets, strengths and points of pride, and learning how "business gets done." Understanding the community helps identify individuals and groups whose support is necessary, including who to approach and involve in the initial stages.

Many communities engage in coalitions and partnerships developed around specific issues. These include efforts such as management of chronic health conditions, prevention and treatment of substance abuse, raising awareness of depression, the COVID-19 pandemic and vaccine readiness, and community and economic development. It is important to consider how attempts to engage or mobilize the community around new issues may build on or affect these preexisting efforts.

What is Necessary for Engagement to Occur

Principle 3. Build and maintain relationships and trust by working with individuals and/or community leaders.

Learning how communities perceive each other and your affiliation will help to identify strengths and address barriers. Local governments, universities, majority organizations, healthcare facilities, and communities themselves have displaced, disregarded, damaged, and demeaned many communities. At the same time, many of those entities have access to resources and personnel that could benefit the community. There are many ways to learn about the community's perceptions of those starting a project and to lay foundations for genuine partnerships (Community Tool Box, Center for Community Health and Development at the University of Kansas, n.d.).

The literature on community participation and organization discussed in Chapter 1 indicates that positive change is more likely to occur when community members are an integral part of a program's development and implementation. All partners must be active participants and respected from the start. Meeting with and working alongside key community leaders and groups at their organization or in their community setting helps to build trust. Collaborating allows organizers to become more knowledgeable about the cultural needs of the community, its concerns, and the factors that will help or harm participation. In addition, community members need to see and experience "real" benefits for the extra time, effort, and involvement they give. When engagement leaders establish a successful relationship, meetings and connections with community members can build into an ongoing and substantive partnership.

When connecting with the community, it is worth the time to think carefully about community and stakeholder engagement. There is often more than one church, gay bar, barbershop, or school nurse in communities. Think about involving a select group, but not only one of each; there is often variation within, as well as between, community groups and members.

It is essential for those engaging a community to keep to the highest ethical standards. Under some circumstances, community engagement might itself be considered an ethical requirement. The rights, interests, and well-being of individuals and communities must have highest priority. Communities are aware of and sensitive to past ethical failures, such as the 1932 Tuskegee Study of Untreated Syphilis in the Negro Male, now referred to as the "United States Public Health Service Syphilis Study at Tuskegee," where unconsented black men with syphilis were left untreated, even though a cure was available, "to study the natural course of the disease" (Centers for Disease Control and Prevention, n.d.). This long history of egregious acts under the name of "research" has resulted in understandable distrust among some communities and has produced challenges for community organizers in partnership and beyond. Additional examples include the story of Henrietta Lacks (Johns Hopkins, n.d.), whose cells were taken without her knowledge and have been used in experiments for decades without consent of the patient or payment to the family. Ethical conduct is the foundation for engagement; without it, researchers can harm communities and perpetuate division and distrust (Lichtenfeld et al., 2019). On the other hand, some communities, led initially by ActUp (HIV and AIDS activists) and currently the rare disease communities, are demanding research so that medical advances benefit all, health disparities are reduced, and cures are found for people living with these conditions.

Principle 4. Remember and accept that collective self-determination is the responsibility and right of all people in a community. No external entity should assume it can bestow on a community the power to act in its own self-interest.

An organization, institution, or individual aiming to partner with a community must view community members as experts and recognize that strategies and solutions must be for the community and by the community. This community-partnered approach occurs when members of the community are the architects and decision-makers guiding that initiative. Partner autonomy (or control) is central to achieving shared leadership. However, establishing this can be complex because communities may have factions that compete for power and influence. Internal and external forces may be at play in any engagement effort. As addressed in Principle 6 (below), many ideas may be challenged and negotiated throughout the engagement process.

The literature on shared or distributed leadership strongly supports the idea that problems and potential solutions should be defined by the community (Liang & Sandmann, 2015). Community members need to be engaged in the entire process of defining the issues, identifying action areas, planning and implementing strategies, and evaluating outcomes and refining solutions. Community members are more likely to become involved if they (1) identify with the issues being addressed, (2) consider the issues to be important, (3) feel they have influence and can contribute to solving the issues, (4) encounter few barriers to participation, (5) see that the benefits of participating outweigh the costs (e.g., time, energy, financial costs), and (6) feel supported during their participation in a welcoming organizational climate (Liang & Sandmann, 2015).

How Engagement can be Successful

Principle 5. Establish a partnership with the community to create change and improve health.

A partnership is "a relationship between individuals or groups that is characterized by mutual cooperation and responsibility, as for the achievement of a specified goal" (American Heritage Dictionary, 2018). When the work involves community participation—in its design, implementation, dissemination of findings, and feedback loops—its solutions are community-driven and responsive to the community's economic, social, and political trends and priorities. Furthermore, fair and even partnerships and transparent discussions of power contribute to achieving success (see Principle 4).

Co-learning or collaborative learning involves individuals and groups engaged in exchanging information and building capacity through shared experiences. Each individual obtains and imparts knowledge in a group setting and feels they have something meaningful to contribute to the goal of improved community health outcomes (Cortez et al., 2011).

Principle 6. Recognize and respect the diversity within the community.

Awareness of the various cultures of a community and other factors affecting diversity must be a priority. Strengthening the capacity of populations and their participation as partners means using what already exists in community assets, such as diversity or differences in culture, language, race, ethnicity, age, sexual orientation and gender identity, mobility, literacy, and/or personal interests. For example, recognizing *culture* as an asset means valuing aspects of the community with which people identify and that enhance their sense of belonging. Appreciating what connects people to a group that has shared beliefs, values, and practices in areas such as art, music, language, and stories is essential. Valuing cultural diversity within a community and how culture influences social roles and norms for feeling, thinking, and behaving (Cohen, 2009) not only enhances community participation, but also builds community capacity and collaborative capacity for planning, designing, and implementing solutions. From a prevention perspective, culture acts as a protective factor increasing resilience when facing life challenges.

To develop an effective and appropriate partnership between institutions and the community, a shared understanding of the community context is needed, including getting information and histories that will inform a context-appropriate approach (London et al., 2020). Community dialogue among partners is one strategy. Understanding contexts supports relationship-building and project planning and design, implementation, evaluation, and fine-tuning so that the project remains relevant to the community's cultural, language, and contextual needs.

These elements of diversity may affect individuals' and communities' access to health care delivery, health status, and response to community engagement efforts. As indicated in Chapter 1, the processes, strategies, and techniques that engage a community must respect and be aligned with cultural traditions. The systems perspective suggests attention to another element of community diversity: the heterogeneity of populations and the many roles that different people and organizations play in the functioning of a community. Engaging diverse populations requires working alongside them to identify the most appropriate ways to initiate and sustain engagement.

What is Necessary to Sustain Community Engagement Efforts

Principle 7. Identify and mobilize community assets and strengths through developing the community's capacity and resources to make decisions and take actions.

Community assets include the information, interests, skills, capacity, resources, and experiences of individuals and local organizations, as well as the networks of relationships that connect them. The discussion of community participation in Chapter 1 highlights the need to offer an exchange of resources or incentives that meet community interest and ensure community participation. Depending on the impetus for the engagement process (e.g., a funded mandate vs. a more grassroots effort), resources are likely to vary (Magis, 2010).

Although it is essential to begin an engagement effort by using existing resources, the engagement is more likely to be sustained when new resources and capacities are developed. Engaging the community in making decisions about health and taking action in that arena may involve making available experts and resources to help communities develop the necessary capacities, and infrastructure to analyze situations, make decisions, and take action.

Principle 8. Recognize that individuals and institutions must be prepared to release control and be sufficiently flexible to meet changing needs.

Engaging the community is ultimately about facilitating action, which should include mobilizing the many elements of a community needed for the action to be sustained, while still creating a manageable process. Community engagement will change relationships in the way that institutions and individuals demonstrate their capacity and strength. In environments characterized by dynamism and constant change, coalitions, networks, and new alliances likely will emerge. Those implementing efforts to engage a community must be prepared to anticipate and respond to these changes and make explicit plans to sustain the change after the funding, program, or project has ended.

Principle 9. Foster community collaboration and strengthen long-term commitment among the partners.

Community engagement sometimes occurs around a specific, time-limited initiative, and the level and type of participation can differ. More commonly, however, community participation and mobilization need nurturing over the long term. Long-term partnerships have the greatest capacity for making a difference in the health of the population. Building trust and developing capacity and infrastructure for successful community action takes time. Both large medical organizations and strong community partners have much to offer and much to learn. Strategies must be developed for sustaining efforts; though grants may end, the engagement and relationship should remain. Doing so can strengthen the foundation for future work. The probability of sustained engagement and effective programming increases when community participants are active partners in the process (Bergstrom et al., 2014).

Principle 10. Demonstrating trustworthiness is fundamental to sustaining successful community engagement.

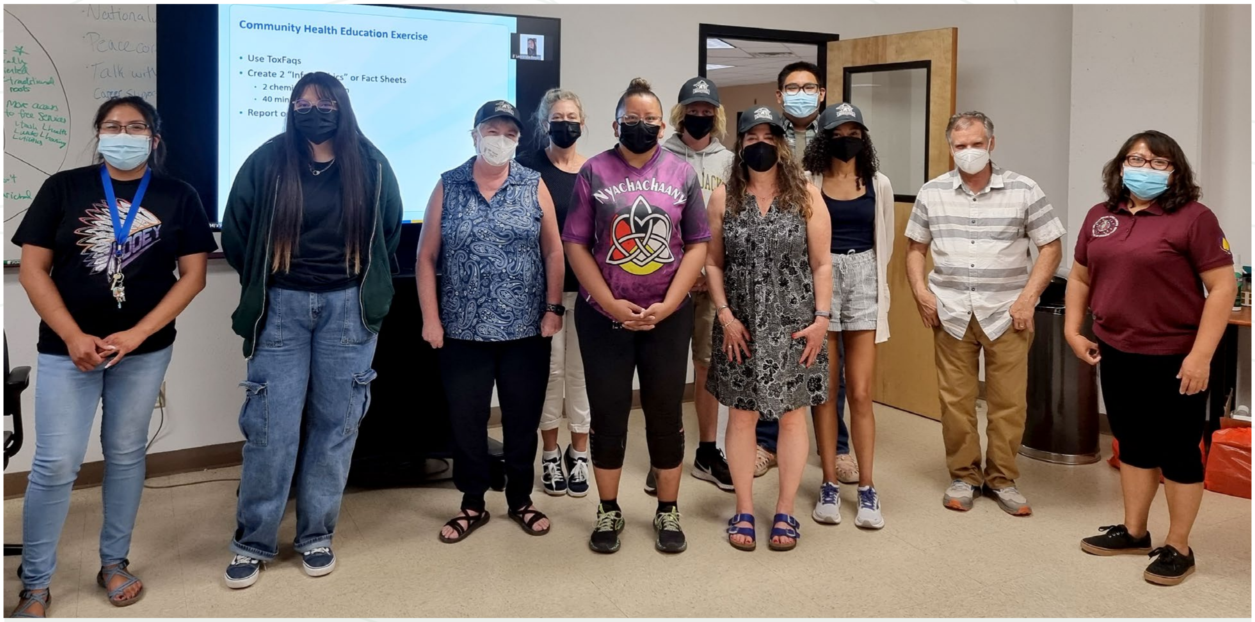
Trustworthiness is essential to forming effective partnerships and, over time, will deepen commitment through building relationships based on empathy, honesty, respect, and humility (Wilkins, 2018). Partnerships built around deliberative means of engagement and bidirectional communication are required for trustworthiness (Cheung, 2018). The individuals and institutions that are successful in effectively engaging and mobilizing communities and building coalitions of community leaders are those that allow for power to flow from the bottom up, have a foundation of trustworthiness, and have a genuine commitment to community participation. A bidirectional model of community engagement requires communication and allows the community to control their agenda, define their community needs, and make decisions (Sabatello & Appelbaum, 2017).

As highlighted in Principle 5, people seek change that is meaningful and beneficial to their community. When given the opportunity to participate fully in managing community-based projects, they become experts in coming up with solutions and addressing inequities. For individuals and institutions seeking to work alongside these communities, trustworthiness means that key partners and decision-makers become fully immersed by going inside communities and engaging with people in their neighborhoods, places of employment, places of worship, etc. There are no stand-ins in community engagement. Some structural efforts may enhance engagement, such as community advisory boards (CABs), the use of community health workers as navigators, or hiring people from the community to work on the project or in the program. Though these are essential, the entire team must embrace the principles for the engagement to work. The primary and head of the project must be as committed as the community health worker. Everyone on the team must earn the community's trust, and anyone on the team can lose it.

A useful resource on the principles of trustworthiness has been produced by the Association of American Medical Colleges. Their Center for Health Justice website includes a free, downloadable toolkit and discussion guide on the principles of trustworthiness (Association of American Medical Colleges Center For Health Justice, n.d.).

Chapter Conclusion

In this chapter, we discussed 10 principles that are essential to the success of community-engaged health promotion and research. The specific applications of the principles will vary based on culture, project, and setting. However, agreed-upon principles serve as a critical framework for ensuring that all parties remain mindful of each other's values, differences, and agendas. The next chapter will provide examples of how these principles have been applied in specific collaborative efforts.



Summer interns and faculty in a community health education training. *ATSDR, 2022.*

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CHAPTER 3: SUCCESSFUL EXAMPLES IN THE FIELD

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Successful Efforts in Community Engagement

This chapter presents examples of successful community engagement efforts in health promotion, environmental health, and community-engaged research. These examples demonstrate the application of the principles of engagement discussed in Chapters 1 and 2. The projects highlighted in this section embody the principles of community engagement that enhance inclusivity, identify health gaps and disparities, promote community-driven strategies and solutions, and advance health equity.

The book's editors held a national call for examples sent out through networks (such as NIH and the National Center for Advancing Translational Sciences [NCATS]), and local networks such as Community-Campus Partnerships for Health. We selected examples from those submitted, scoring them to according to:

a) Scalability
b) Alignment with the 10 principles of community engagement
c) Evaluation, measures, and impact
d) Lessons learned

We included two national programs, the *All of Us* Research Program and Helping to End Addiction Long-term (HEAL) as examples of a large, government effort to address urgent community priorities and promote diversity, inclusion, and equity in research.

Some contributors cited specific principles of community engagement used in their work as outlined in Chapter 2. All contributors demonstrated integration of community engagement practice, successes, and challenges. The views, opinions, and contents of each example are solely the responsibility of the case study authors and may not represent the position of the funding organizations.

Students learning environmental site assessment to improve community health.
Lloyd DeGrane, 2019.

Programs that Involve Community Youth

Two programs sought to involve the youth of the community. One addressed the Flint, Michigan water crisis, and the other addressed rural health in Kentucky.

Example: Building Youths' Capacity to Address Environmental Justice and Improve Mental Health (The Flint YPAR EJ Program)

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Background and Purpose

African American youths between the ages of 10 and 19 who live in low-resource neighborhoods experience multiple stressors. These stressors result in emotional and physical traumas that influence their psychosocial and mental health (Healy & Bernstein, 2016). Such traumas make it difficult for youths to cope with new disasters, such as environmental hazards, placing them at greater risk for adverse health than those who do not share trauma exposures.

In 2015, youths were visibly missing from the debate regarding strategies for addressing the Flint, Michigan water crisis. At this time, the town's water supply was contaminated with lead. Our organization, the Center for Research on Ethnicity, Culture, and Health (CRECH), has a 20-year history of academic-community partnerships. We explored youth perspectives around the Flint water crisis. CRECH worked with community partners, such as the Flint Odyssey House–Health Awareness Center, the Flint Fathers and Sons steering committee, and other Flint community-based organizations. Together we conducted community forums with local youths focused on their experiences stemming from this crisis. Researchers from the University of Michigan and the community members who participated in the community forums conceptualized, collaboratively developed, and implemented the Flint Youth Participatory Action Research Environmental Justice Program (Flint YPAR EJ).

We used a Youth Participatory Action Research (YPAR) strategy to train Flint youths to create questions about environmental justice (EJ) issues and devise strategies for addressing them. YPAR is a form of CBPR that engages youths as equal partners in the research process with adults from community and academic partner entities.

Methods

We started the project by holding youth community forums organized by all partners to determine youth perspectives on the Flint water crisis. From the youth community forums data (Muhammad et al., 2018), the CRECH team developed a training curriculum for 20 youths to understand and address EJ in their community. By using a YPAR strategy, the team trained the youths of Flint to become citizen scientists. This empowered them to examine and generate solutions to problems for community change and enhanced their psychosocial development. Community partners helped shape the project. They recruited youths through their organizations, participated in the research training, and assisted with oversight of youth field projects. Youths, in partnership with trained community leaders, collected data (using one or more research method covered in the training, such as Photovoice, observational surveys, and soil testing) to develop answers to their research question. Most youth-selected projects focused on outdoor or indoor projects. Outdoor projects included soil sampling in the community and indoor projects included contamination in public buildings. Each group spent an additional day preparing a Photovoice poster to present their findings and recommendations at a public community forum held in Flint. Youths also completed pre- and post-surveys that assessed several variables, including life control, mental health, and social support indices.

Results/Outcomes

The results from the participants in the Flint YPAR EJ program showed a statistically significant increase in perceptions of:

- Black identity
- Community involvement
- Sense of community belonging
- Perceptions of the influence of racism/ethnic discrimination on the Flint water crisis

Participation in the program increased a sense of community belonging in both males and females. Other outcomes were life satisfaction and perceptions that racial discrimination influenced the Flint water crisis. Overall, the participating youths benefited from being part of the Flint YPAR EJ Program. They rated the program experience excellent, or very good. Related to addressing the water crisis through recommending changes in their community, 85% of the youths felt prepared to advocate for change. Additionally, the activities enhanced the youths' self-efficacy. Two--thirds of the youth reported feeling confident in their ability to speak with decision-makers regarding changes to improve the quality of life in their community. Finally, after participating in the Flint YPAR EJ Program, all of the youths indicated that they would consider careers in environmental health sciences, public health, or medicine.

Application of the Principles of Community Engagement

The community partners identified a desire and need to participate in an intervention. All partners got involved with creating and disseminating project-related products, including publications and community presentations. The 20-year collaboration between university and community partners created several programs over the years to promote health in the Flint community. The historical relationship allowed the seamless pivot to focus on an emerging threat (the water crisis) and address health disparities. Because of the strong relationships and history of work with the youth population, the community partners were successful in identifying and addressing the ongoing needs. The partnership members shared a mutual commitment that allowed them to improve the health of the Flint community—particularly black youths and their families—and beyond.

The academic-community partnership is an authentic collaboration, which over time forged a relationship based on trust. We meet monthly to discuss focus areas that align with the community's needs. Through our partnership, all elements of the work emerge, such as the community forums that formed the backbone of our current program. We have mutual respect for each other. We trust the true intentions of all members toward community benefit. This is evident in the inclusion of each partnership member's voice and perspective on the program. The Flint YPAR EJ program seeks to help youths translate scientific discoveries into community benefit.

Example: Growing Appalachian Teens as Environmental Scientists (GATES)

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Background and Purpose

Rural Appalachia Kentucky (KY) has some of the nation's highest rates of preventable disease (e.g., lung cancer, COPD, diabetes, cardiovascular disease). These diseases are all linked to environmental exposures to dangerous substances. People in Appalachia also experience persistent poverty, low levels of educational attainment, and high levels of unemployment (Marshall, Thomas, Lane, et al., 2017). These conditions exacerbate environmental exposures. Engaging high school-aged youths in exploring their health and the environment that surrounds them can result in enhanced knowledge and skill development, critical awareness, and opportunities for practicing positive health behaviors and policy change (Cardarelli et al., 2021). In 2017, researchers from the University of Kentucky Center for Appalachian Research in Environmental Sciences (UK-CARES) initiated a relationship with the Perry County school system in rural Appalachia KY. The partnership aimed to engage and train high school students in becoming active community participants in environmental health science research. This initial partnership grew into an established, productive community-engaged collaboration: Growing Appalachian Teens as Environmental Scientists (GATES). The goal of GATES is to equip high school students as citizen scientists with the skills and knowledge to conduct research that addresses community environmental health concerns and to communicate findings about environmental health back to Appalachian KY residents. The aim is to reduce health disparities. Initial collaboration involved testing the feasibility of training high school students to monitor indoor and outdoor air quality using real-time, low-cost air quality devices. The incidence of lung cancer in the Appalachian region in general is high. Combined factors such as a high prevalence of smoking and secondhand smoke as well as high levels of radon are leading causes of lung cancer (Stanifer, Rayens, Wiggins, et al., 2022). Radon is a naturally occurring environmental carcinogen. GATES students chose to focus on community radon exposure for one of their first environmental health studies.

Methods

GATES students and their high school biology teacher engaged in a cross-institution project between two National Institute of Environmental Health Sciences (NIEHS)-funded Environmental Health Sciences Core Centers. The purpose of this community-engaged collaborative was to assess the feasibility of using a youth citizen science approach in the school setting. The approach was to raise awareness of home radon testing. Then, the collaborative would assess the agreement between indoor radon values collected by community members and exterior soil samples collected by the Kentucky Geological Survey (Hahn et al., 2020).

The collaborative educated 100 high school students in rural Kentucky (GATES team) and suburban Ohio in human subjects protection. Students interested in serving as citizen scientists obtained parental consent to participate. The students participate in training on the basics radon exposure, testing, data collection, mitigation, and the evaluation and reporting of results. The citizen scientists then recruited homeowners in KY and Ohio to complete a 15-minute online survey and to install short-term, charcoal-based home radon detectors. The survey asked the homeowners to assess home characteristics and perceived risk related to radon.

Results/Outcomes

Two students conducting a site assessment. *Lloyd DeGrane, 2019*.

Just over one fourth of the students (27), obtained parental consent to participate as youth citizen scientists in the radon project. The youth citizen scientists recruited 18 homeowners to complete an online survey and test their homes for radon. Of the 18 homeowners who completed the online survey, 15 returned a radon test kit that yielded results ranging from less than 14.8 becquerels per cubic meter (Bq/m3) to 277.5 Bq/m3. The students compared radon values. The U.S. Environmental Protection Agency's (EPA) action level is 148 Bq/m3. The World Health Organization (WHO) action level is 100 Bq/m3. Two tests exceeded the EPA action level, and two tests exceeded the WHO action level. The collaborative provided $1000 vouchers to homeowners with radon levels above the action level to purchase radon mitigation systems. The collaborative also provided long-term charcoal-based test kits (90 days to one year) to homeowners who were above the WHO action level but below the EPA action level (Hahn et al., 2020).

The students completed evaluation surveys. The surveys demonstrated that students were satisfied with the training sessions and the overall learning experience (Hahn et al., 2020). Students were successful in communicating findings with peers, residents of rural Appalachia KY communities, and the scientific community. They presented findings at the Appalachian Research Day conference (regional; Wilmhoff et al., 2019), the Kentucky Children's Environmental Health Summit (state), and the NIEHS Partnerships for Environmental Public Health (PEPH) annual conference (U.S. national). The students also produced a video describing their first air quality project.

After their first air quality study, GATES students noticed high levels of particulate matter inside and around their school buses. They planned and implemented another citizen science project to examine air quality on pre- and post-Diesel Emissions Reduction Act- aged school buses. The school bus study resulted in the school system saving approximately $130,000 on the purchase of three new low-emission school buses from a Volkswagen settlement. This resulted in a $13 to $1 return on investment. The Perry County Central High School students project successes earned the 2020 UK-CARES and UK CERH Community Engagement Award in Environmental Health Sciences. The award recognizes individuals or community-academic teams who demonstrate effective research or project evaluation to improve environmental health in Appalachia KY. GATES students and their teacher recently launched a third community-academic collaboration. This collaboration addresses water quality concerns by examining local streams contaminated by wastewater run-off from homes. The school bus air and water quality studies resulted directly from concerns expressed by the GATES students. The GATES high school teacher co-authored two publications about the GATES student work in an international, peer-reviewed journal (Cardarelli et al., 2021; Hahn et al., 2020). Youth engagement can provide an opportunity for community-engaged research that may not be available otherwise when using traditional research methods.

Challenges and Lessons Learned from Both Youth Programs

Engaging youth in citizen science can be rewarding but also challenging because of student school schedules and involvement in extracurricular activities. Further, human subject protection policies, such as obtaining parental consent and training requirements, may be hurdles in engaging youth. To minimize these barriers, it is critical to coordinate with an adult mentor (e.g., teacher, youth leader, coach) who has daily contact with the youth involved. Coordinating schedules and arranging times when students can participate are critical to devising a successful youth-based citizen science program. Adult mentors may aid in bridging communication gaps that may exist between youth and investigators. Acknowledging the active role of the youth enhances understanding of their important roles in the studies and in improving their own environment.

Implications for Advancing Health Equity

Appalachia KY and Flint, Michigan are low-income regions with low educational achievement and poor access to health care providers and health systems. By design, the collaborative programs engaged youth in addressing environmental health concerns. The programs equipped high school students with the knowledge and skills necessary to conduct environmental health research as citizen scientists. The programs trained students in ethical research practices and human subjects protection principles. The training included additional skills of instrumentation use, data collection, analysis, and report back.

Through UK-CARES's commitment to the communities of rural Appalachia KY, the GATES program has empowered and educated more than 100 Appalachia KY high school students to help combat the environmental exposures that can lead to preventable diseases. Many students who participated in Flint YPAR EJ program and the GATES are now pursuing health care-related professions.

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Several examples demonstrate how environmental justice, environmental health, and community engagement work together to improve health in communities.

Example: Restoration in Graniteville through Supportive Engagement (The R.I.S.E. Project)

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Background and Purpose

On January 6, 2005, Graniteville, a small unincorporated town in rural South Carolina, made headlines. A freight train derailed and discharged an estimated 60 tons of chlorine gas. The derailment subjected 5,400 residents within a one-mile radius to a mandatory evacuation. The residents could not return home for one to two weeks. As a result of injuries incurred from direct chlorine inhalation, at least nine individuals died, and about 550 sought immediate medical assistance. To document the long-term effects of the chlorine spill, a new partnership emerged, Restoration in Graniteville through Supportive Engagement (R.I.S.E). The R.I.S.E. project partnership was formed among researchers at the University of South Carolina (UofSC), the Graniteville Community Coalition (GCC), community investigators, and a community advisory board (CAB). R.I.S.E collaboratively documented effects of the spill on the community's health (e.g., respiratory health outcomes and stress). R.I.S.E. also documented the spill's long-term impacts on quality of life, changes in economic infrastructure and opportunities, and access to health care.

Methods

To guide our process, R.I.S.E. used a community-engaged approach informed by the CDC *Principles of Community Engagement* (second edition, 2011). The primary methods included Photovoice with community residents and semi-structured interviews with local health care providers. To increase community engagement and support, key members in our academic-community partnership included the UofSC, GCC, community investigators, and a CAB formed for the R.I.S.E. project.

Results/Outcomes

Residents photographed and reported more negative than positive images of the long-term impact of the disaster on their quality of life. Overarching themes included:

- Economic decline because of the closure of businesses and the resultant loss of jobs
- Safety concerns
- The need for workplace modernization

Concerns about physical health (specifically, cancer and respiratory illness) were the most prominent themes from both Photovoice and the health care provider interviews. Community residents reported having concerns with mental health challenges. Healthcare providers also noted mental health challenges. In the years post disaster, we continued to work with many community members and organizations. Eventually, some community members became integrated into the R.I.S.E. project team and served as paid project consultants. The community members also co-authored papers and presented at local and national research conferences and community meetings. R.I.S.E. raised 10 million dollars to support local infrastructure and conduct research. The partnership has grown to include other constituents positioned to help revitalize Graniteville.

Emergency response agencies should consider these results as they develop strategies to help identify where to focus disaster response efforts in the immediate aftermath and longer-term recovery period of technological disasters. These results may be particularly relevant for underserved rural communities.

Application of the Principles of Community Engagement

Principle 1. Our primary goal was to effect long-term sustainable positive health outcomes in Graniteville and the surrounding community post disaster. Once we established this goal, endeavors such as grant proposals, health fairs, and other health initiatives could be easily planned with the support of partners.

Principle 2. R.I.S.E. conducted several town hall meetings in the months after the disaster for community members to voice their concerns about the recovery (or lack thereof). These meetings provided opportunities to network with Graniteville community members and agency representatives while addressing community concerns. These meetings also generated important information about community norms and values, pre- and post- disaster demographic trends, economic conditions, and formal and informal political structures.

Principle 3. Our community investigators and CAB members helped the team navigate potential risks and align with best practices to strengthen relationships with key partners and build trust within the community. These relationships allowed us to gain stronger commitment and support from influential community members and organizations to help achieve our program goals. We established formal memorandums of agreement and less formal letters of commitment to document our growing relationships with community members and constituents. These partners' declarations of support were essential in producing momentum for gaining broader community support.

Principle 4. We were clear that our role was not to "bestow" power but to engage in a process whereby community members could tap into their own power to express their voices and make change. We emphasized the importance of community members leading the process of problem identification. Our role was to attempt to translate those important areas of interest and make connections to key partners, human resources, or financial resources.

Principle 5. Primary formal partners included those mentioned as key partners. However, other less formal partnerships with local churches, businesses, schools, health centers, and nonprofit organizations were equally important. These partners did everything from providing door prizes for community events to assisting with participant recruitment for research projects. The GCC, in partnership with our community investigators and a local church, worked together to receive grants to build community capacity in the Graniteville area.

Principle 6. By design, our partnership reflected the diversity of the community we served. The intent was to initiate and sustain collaborative relationships throughout the Graniteville community.

Principle 7. As a result of our partnership, our team helped with the community's capacity to obtain grant funding and take political action (by petitioning to formally incorporate the town). Our team also helped to conduct community health fairs, develop a local newspaper, coordinate a community garden, and reconstruct the Graniteville water system.

Principle 8. UofSC team members who wanted to conduct research in Graniteville had to ensure that partners supported project goals and protocols. UofSC team members pursued research endeavors using a community-based participatory lens. Through this lens, the aim was for the community to help develop, implement, and evaluate any projects conducted by the team in the Graniteville area. While we had specific goals to achieve as promised to our funders, we planned to be flexible in our approaches to respect and reflect the needs of the community.

Principle 9. More than 15 years post disaster, we continue to work with many of the same community members and organizations as in the initial days after the disaster. We helped the community receive funding to support local infrastructure and conduct research. We also continued to grow the partnership to include other constituents positioned to help revitalize Graniteville.

Principle 10. Our community investigators and CAB members helped the team navigate potential and actual risks. We collaborated to align with best practices to initiate relationships with key partners in the community. Our long-term involvement and visibility within the community, coupled with addressing major concerns early and often, helped us become trustworthy. At the same time, collaboration helped build relationships and trust between team members and the community.

Challenges/Lessons Learned

We were guided by the lessons that we learned through our long-standing partnership and the community engagement principles noted above. From these lessons, we recommend the following for other academic institutions and communities seeking rewarding, long-standing partnerships:

- Address major concerns early and often to build trust and understanding. Collectively devise solutions for addressing concerns.
- Stay visible. It is difficult for partners to maintain trust if they do not view academic institution members as being consistent in their interest and engagement.
- Do not allow conflicts and political fracturing to influence team dynamics. Remain united toward the partnership's common goal.
- Embrace the demographic and ideological diversity of partners.
- Invite new members to join the partnership to prevent service fatigue and to receive new perspectives.
- Show appreciation of partners often.
- Even in the face of limited resources, identify assets within the community to avoid the perception of trying to "bestow" power.
- Be flexible. People may change, needs may change, and goals may change.
- Remain enthusiastic about long-term commitment and engagement.

Implications for Advancing Health Equity

To advance health equity is to promote an environment that aims to address and eliminate health disparities. The most effective, sustainable means of doing so is through influencing structures and promoting social justice. Our team focused on a systems-level impact to help advance health equity for the people of Graniteville. We collaborated with community members to create long-lasting projects in the community. Our team helped build the community's capacity to obtain grant funding, take political action, conduct community health fairs, develop a local newspaper, coordinate a community garden, and reconstruct the Graniteville water system.

Example: Rochester Healthy Community Partnership COVID-19 Work Group

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Background and Purpose

In 2004 the Mayo Clinic in Rochester and the Hawthorne Education Center (an adult education center that serves new immigrants) established the Rochester Healthy Community Partnership (RHCP) as a community-academic partnership. This partnership matured by formalizing operating norms, adopting CBPR principles, and adding partners from many sectors. RHCP has developed a community-based research infrastructure that has helped with research training for community partners. Community and academic partners jointly conduct every phase of research, disseminate results, implement sustainability plans together, and co-author scientific products. RHCP has obtained funding for many partner projects in recent years. For example, the following projects helped:

- Strengthen the CBPR partnership to develop culturally tailored educational materials about tuberculosis (2008)
- Improve diet and physical activity among immigrant groups (2011)
- Improve diabetes self-management in Latinx patients by using a digital storytelling intervention (2018)
- Test a community-derived social network intervention to reduce cardiovascular risk in immigrant populations (2021)

At the start of the COVID-19 pandemic, RHCP community partners observed that credible COVID-19 information was available but not reaching immigrant communities in Olmsted County, Minnesota. In addition, RHCP also observed that 30% of positive COVID-19 tests were among the Black and Hispanic population, although they represented only 16% of the population. RHCP partners launched a project to ensure that COVID-19 information was more equitably distributed, with a focus on reaching immigrant communities, including Black and Latinx immigrants.

Methods

In March 2020, RHCP formed a community-based COVID-19 workgroup to co-create an intervention to reduce pandemic inequities. The workgroup consisted of 24 communication leaders (CLs). The CLs represented six community partner groups (Somali, Anuak, Cambodian, Latinx, Ethiopian, and South Sudanese), academic partners, and county and city officials. Partners adopted a crisis and emergency risk communication (CERC) framework[1] to reduce COVID-19 disparities. Partners aimed to co-create and disseminate public health messages, enhance connections to existing resources, and incorporate community voices in regional pandemic mitigation policies.

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[1] The Centers for Disease Control and Prevention crisis and emergency risk communication report is suggested as a resource for readers: CDC CERC: https://emergency.cdc.gov/cerc/

RHCP community and academic partners jointly developed COVID-19 messages across three constructs: prevention, testing, and socioeconomic impacts. Bilingual CLs delivered messages within their social networks through virtual platforms. Message recipients were encouraged to further amplify messages through their social networks. CLs asked about health and socioeconomic concerns through the same platforms. CLs and RHCP partners met regularly to share their progress on emerging best practices, refine messages, use resources, and advise policymakers.

Results/Outcomes

RHCP community leaders and health experts co-created and disseminated COVID-19 messages through their social networks. Over the first 14 days of the intervention, 24 CLs delivered messages in 6 languages across 9 electronic platforms to over 9,800 individuals within their networks. Communication leaders' feedback resulted in changes to regional policies that simplified testing processes and improved provision of essential services (e.g., food, housing). In 2021, RHCP and Mayo Clinic collaborated, using the same bidirectional platforms to implement 7 community-based COVID-19 vaccine clinics.

Data from a mixed-methods evaluation showed that the CERC intervention was acceptable and effective. The intervention was adapted and sustained for 18 months. Framework implementation led to system and policy changes to meet the needs of immigrant and refugee populations. (Wieland ML, Asiedu GB, Njeru JW, Weis JA, Lantz K, Abbenyi A, Molina L, Ahmed Y, Osman A, Goodson M, Torres-Herbeck G, Nur O, Porraz Capetillo G, Mohamed AA, Sia IG. Community-Engaged Bidirectional Crisis and Emergency Risk Communication With Immigrant and Refugee Populations During the COVID-19 Pandemic. *Public Health Rep*. 2022 Mar–Apr; 137 (2):352–361 Epub 2022 Jan 13 PMID: 35023414 PMCID: PMC8900245 https://doi.org/10.1177/00333549211065514

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Other community-academic partnerships in Minnesota, Florida, and Mississippi adapted the RHCP CERC intervention to target additional populations disproportionately affected by the pandemic throughout the country (Washington R, Weis JA, Monger M, Burse N, Melvin SC, Omondi AA, Lohr AM, Njeru JW, Compretta CE, Sia IG, Wieland ML. Adaptation of a bidirectional crisis and emergency risk communication framework by community-engaged research partnerships in rural Mississippi during the COVID-19 pandemic. *J Clin Transl Sci*. 2023; 7 (1):e79 Epub 2023 Feb 08 PMID: 37125068 PMCID: PMC10130849 https://doi.org/10.1017/cts.2023.15)

Application of the Principles of Community Engagement

This project reflects a 20-year community-academic partnership that has iteratively built capacity to operate according to Principles 1–8. The intervention's application to Principle 9 highlights how long-standing community-engaged research partnerships are uniquely positioned to respond to public health crises. Such partnerships have access to academic partners' expertise in disease content and community partners' organizational and technical capacity to interact with disproportionately affected populations in research and evaluation. The foundation of the longitudinal partnership embodied trustworthiness (Principle 10), which contributes to sustainability and agility in challenging times.

Challenges/Lessons Learned

The work of RHCP faces challenges from the effort and resources required by community and academic partners to initiate the intervention in real-time. The community and academic partners communicated frequently. This allowed the team to respond rapidly to concerns and obstacles. Bidirectional communication helped connect community members to resources through group-based troubleshooting. Bidirectional communication also resulted in systems and policy changes to meet the needs of immigrant and refugee populations.

Implications for Advancing Health Equity

Community-engaged research partnerships can effectively use their social networks, credibility, and technical expertise to promote bidirectional communication with groups at risk for pandemic health inequities.

Example: University of Florida HealthStreet Community Engagement Model

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Acknowledgments for leadership in this project: Community Health Workers and Community Members

Background and Purpose

In 1989, Dr. Linda Cottler at Washington University in St. Louis founded the initiative HealthStreet to address the current health concerns and needs of the community. In 2006, HealthStreet scaled up for the Clinical and Translational Science Award (CTSA) Program to reach community members who did not have access to needed health care. The HealthStreet model proactively discusses opportunities for people underrepresented in the research enterprise to plan and participate in studies. In 2011, HealthStreet expanded to the University of Florida (UF), through the community engagement program of the UF Clinical and Translational Science Institute (CTSI). HealthStreet's mission is to reduce disparities and improve the health of our community. HealthStreet does this by bridging gaps in health care and health research, through a sustainable presence and our 4 pillars:

1) **To assess needs and concerns from community members themselves (Listen)**
2) **To link people to medical and social services and opportunities to participate in research (Serve the Community)**
3) **To foster multidirectional communication (Educate/Learn)**
4) **To be a trustworthy partner (Trustworthiness)**

Methods

The backbone of the HealthStreet model is the Community Health Worker (CHW). CHW's meets people where they are, using a fleet of 2 Mobile Health Vehicles, and 4 minivans. The CHWs go to laundromats, bus stops, community centers, shelters, food distribution centers, health fairs, parks and other public settings. They interview people with a health needs assessment that covers social determinants, health history and perceptions of research. Based on the needs and concerns the community members voice, the CHWs offer tailored medical and social service referrals. The CHWs inform the community members about UF research studies they may be eligible to participate in. HealthStreet also offers free and confidential HIV testing, blood pressure screenings, health education, items from the clothing closet, a toiletry pantry, and vaccinations, among other services. CHWs conduct follow-up surveys at 60 and 120 days after baseline to evaluate people's experience, satisfaction level, and barriers to access services.

HealthStreet engages with student groups, clinical department services, Safety Net Organizations, faculty members, and community members. Our significant social media presence, website, and newsletter shares information about upcoming events, facility services, and research findings. Another initiative of HealthStreet is *Our Community, Our Health* (OCOH), a national town hall that facilitates multidirectional communication between community members and researchers.

Results and Outcomes

To date, our Florida HealthStreet Registry of community members is about 14,000. We have enrolled 2,900 participants into various research studies. We provided over 55,000 medical and social service referrals and over 64,000 services. Our members are 60% African American/Black, 60% female, and 12% are from rural communities. The team has about 50 publications regarding outcomes that matter to the community and health disparities. Trust has been increasing since 2013. Currently, less than 3% of members rate their trust in both research and researchers in the "low" range. Over 96% of our members have an interest in research. At follow-up, our members rate their satisfaction with their engagement at 3.6 out of 4. Since 2013, HealthStreet has trained 360 students to conduct Community Engaged Research (CenR). The pandemic challenged all CenR programs. In response, HealthStreet moved to the parking lot and offered referrals, Narcan® Nasal Spray Kits, meals, and feminine hygiene products. The model is a trusted source in the community for helping connect people to resources. We share all data on our website, at: https://healthstreet.program.ufl.edu/healthstreet-intiatives/latest-community-health-needs-assessment/.

Applications to the Principles of Community Engagement

Our HealthStreet model aligns with each of the principles of community engagement. We partner with community members and hundreds of community partners to successfully achieve our 4 pillars.

Challenges and Lessons Learned

We have learned to sustain our presence in the community to work with them and to help address the issues that matter to them. The CHWs ask every person they meet with about their top health and neighborhood concerns. We work daily to serve the community to improve disparities in these areas. We also have learned that to be successful, we need to work together with other CE programs across the country. Working together, we can improve population health, one community at a time. With funding from CDC and NIH, our HealthStreet site is leading several national efforts. We are developing training modules for CHWs with academic partners and communications experts (Health Literacy Media). With these initiatives, HealthStreet is at the center, bringing messages to the community and hearing their concerns. This model is working as far away as Bangkok, Thailand where their HealthStreet program is gaining momentum each year (https://www.facebook.com/ChulaHealthStreet-434591346873206/).

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Example: Science Café—Outreach to Understand Translation (SCOUT)

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Acknowledgments for leadership in this project: Nasadir Mohamed, St. Catherine University, and Abdillahi Ganey.

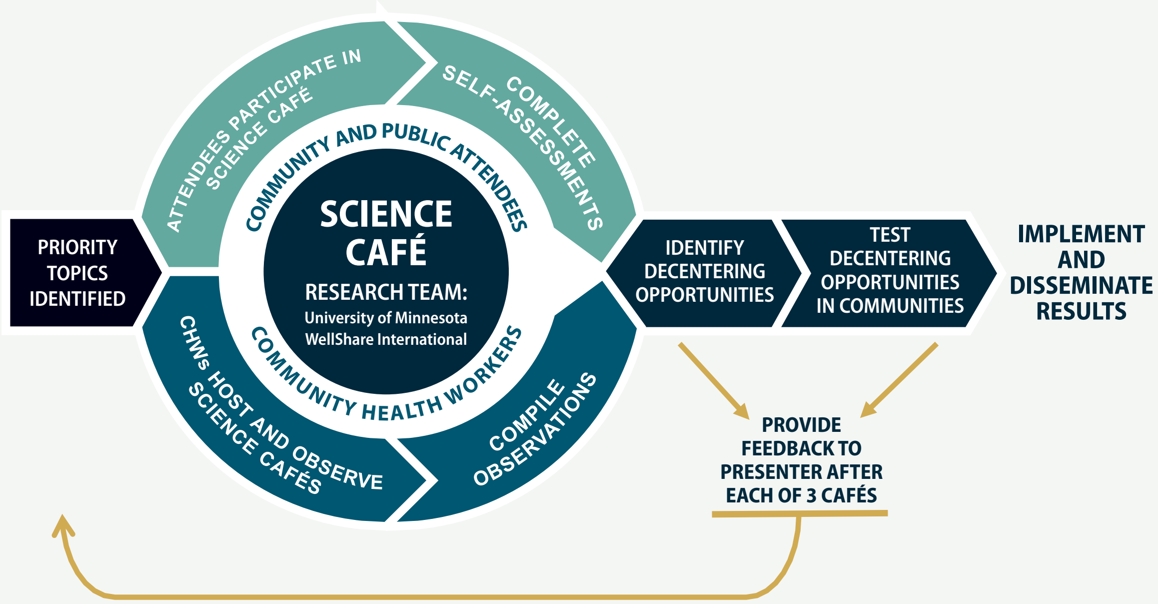
Background and Purpose

A Science Café provides members of the public an opportunity to explore a science topic of current interest with a scientist (Ahmed, 2014). Cafés encourage an atmosphere of informality as people often eat, drink, talk, and learn from scientists and from each other. Cafés are also opportunities for scientists to learn from community members. Cafés occur across the globe but are infrequent in multi-lingual and lower socio-economic communities. Our organizational partner, WellShare International, has for decades worked with immigrant and refugee communities in Minnesota. A WellShare International program officer and three to five community health workers who lived in the communities participated in every planning meeting and Café.

We organized science Cafés for immigrant and refugee community members with limited or no English language proficiency. We aimed to determine if they would discuss health and clinical research topics. Our primary project goal was to study linguistic decentering (Figure 3.1). Decentering recognizes that we can use different words to say the same thing. For example, we could design health messages in two languages. If we found language or cultural barriers, we could change how these messages were worded in one or both languages without giving priority to either language. We wanted to study decentering to see if we could adapt how we talk about health messages in English and make it easier to interpret and translate them into other languages (Wakabayashi 2009).

A community health worker talking with two community members. *Public Health Image Library, 2018.*

Figure 3.1: Linguistic Decentering



Methods

The community-academic research team included bilingual community health workers who engaged in a Delphi process to compile and select six community health issues (Dalkey, 1967). The Delphi process develops a collective view on issues. The research team asked University of Minnesota faculty to develop 15-minute talks about each topic. The research team provided input to help faculty refine their talks. Science Café organizers discourage the use of PowerPoint presentations because they model the power dynamics of the classroom. However, we decided to use PowerPoint and present images rather than text to accommodate the education levels of expected attendees.

The community health workers on the team identified times of the day and appropriate community venues to hold Cafés. They served as event hosts. They welcomed everyone and introduced the presenters. Following the presentation in English and a second language, Café attendees broke into small groups to discuss the topic. Bilingual community health workers observed and made notes based on the language used in the discussions. The groups reported on their discussions and shared their questions with the speaker and each other.

In response to COVID-19, we held the last nine Cafés in a virtual platform. The research team and faculty experts created video presentations. The community health workers both translated and recorded the video presentations. All the videos on a topic contained the same images in the same order. We adjusted the timing of the images displayed to accommodate language differences.

Results/Outcomes

We held 18 Science Cafés on 6 topics in our 3 language communities (Karen, Somali, Spanish). We had 242 total attendees. Over half the participants from each language community reported they spoke no English at home. They also reported that they had from zero to a few years of school-based education.

The opportunity to speak in a language other than English resulted in attendees holding discussions independent of the scientist/expert. This reduced the power of the expert while encouraging the sharing of personal experiences and peer-to-peer learning. The dedication and continuity of community health workers contributed to Café attendance and success. Their ability to observe small group discussions was curtailed by the change to virtual meetings. However, they acknowledged a heightened awareness of word choices. In evaluations of the in-person Cafés, the majority of attendees indicated that they had learned from the topics. Attendees indicated that the Café topics prepared them to learn more.

The Science Café project demonstrated that we could create and deliver cost-effective cultural and linguistic variations of core topical materials for specific communities. The role of community member attendees helped them feel more comfortable. For example, attendees at a Café about incorporating movement and forms of exercise into their daily activities said that they had had enough talk. They advocated putting on a music video. Soon, the entire group proceeded to move and dance for a large part of the session. At another Café about vaccination and (herd) immunity conducted prior to the emergence of COVID-19, attendees said they had not had an opportunity to get a flu vaccine. The project team responded by coordinating with a local community health system to conduct a free Saturday flu vaccine clinic two weeks later. At that clinic, 26 people from multigenerational households received vaccinations. In our experience, building and maintaining relationships depended on active listening and a willingness to respond.

Application of the Principles of Community Engagement

This Science Café project relied on a number of engagement principles. Clarity of purpose, knowledge of communities, and the importance of relationships is evident. We emphasize the role of the community health workers who spoke the language in the development of topics and content. At the Cafés, community members engaged each other in dialogue and sometimes sought further information from the presenter. The structure allowed participants to openly talk in their own language and to reach their own conclusions.

The academic research team members and presenters relied on community partners. They learned from community responses to Café content that diversity occurs both within and between groups. Team members also learned that active listening throughout every partner interaction is a fundamental for developing trust (Lucero 2020).

Engaging community members in research that promotes dialogue revealed new community interests that were not always part of the original project aims. The research team recognized, honored, and incorporated such interests to sustain the partnership. The Vaccines Throughout Your Life infographic exemplifies one project response to a shared need that emerged from the three Cafés on vaccinations and (herd) immunity. Café discussions revealed that attendees from all three communities did not understand the variety of vaccinations commonly administered across the lifespan (see Images 1 and 2). The team translated the infographic into Karen, Somali and Spanish versions. Acting on the opportunity to create community benefit when it arises, even if it is outside a project's specific aims, is one way to demonstrate a commitment to partnership and trustworthiness.

Challenges/Lessons Learned

The social distancing practices implemented in response to the health risks of the pandemic had a deleterious effect on observations as part of the research design. We needed to practice patience and perseverance to raise awareness of how we use language and the role of language in shaping how we think.

Acknowledging the centrality of partnerships in conducting community engaged and participatory research can open up opportunities to advance community health. We learned that we express trustworthiness through our commitment to partners and our willingness to assume responsibility for responding to opportunities when they arise.

Implications for Advancing Health Equity

Science Cafés facilitated access to health information for community members who may not seek out and access information on their own. Café discussions provided opportunities for people to assess information and explore assumptions that shaped their understanding. Discussions also facilitated inquiry into the accuracy and reliability of information. Encouraging dialogue and supporting further inquiry helped connect communities with public health messages. Collective engagement with health messages within communities has the potential to motivate behavior change.

Funding

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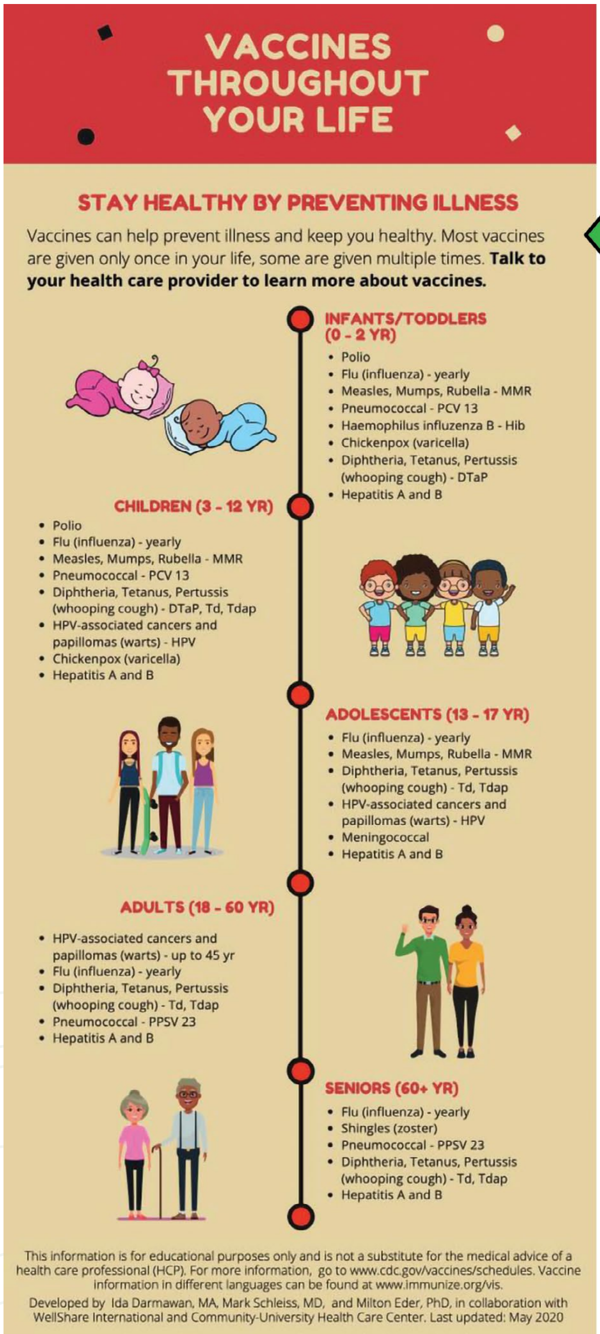
Website

Science Café videos are available in the English, Karen, Somali, and Spanish languages: https://hsjmc.umn.edu/science-cafe

1) **Using the Healthcare System**
2) **Move Your Way**
3) **How do Vaccinations Prevent Diseases?**
4) **Wellness in a Pandemic**

Figure 3. Vaccine Infographics

https://ctsi.umn.edu/news/reimagining-how-engage-immigrant-communities-health-issues



VACCINES THROUGHOUT YOUR LIFE

STAY HEALTHY BY PREVENTING ILLNESS

Vaccines can help prevent illness and keep you healthy. Most vaccines are given only once in your life, some are given multiple times. **Talk to your health care provider to learn more about vaccines.**

INFANTS/TODDLERS (0 - 2 YR)

- Polio
- Flu (influenza) - yearly
- Measles, Mumps, Rubella - MMR
- Pneumococcal - PCV 13
- Haemophilus influenza B - Hib
- Chickenpox (varicella)
- Diphtheria, Tetanus, Pertussis (whooping cough) - DTaP
- Hepatitis A and B

CHILDREN (3 - 12 YR)

- Polio
- Flu (influenza) - yearly
- Measles, Mumps, Rubella - MMR
- Pneumococcal - PCV 13
- Diphtheria, Tetanus, Pertussis (whooping cough) - DTaP, Td, Tdap
- HPV-associated cancers and papillomas (warts) - HPV
- Chickenpox (varicella)
- Hepatitis A and B

ADOLESCENTS (13 - 17 YR)

- Flu (influenza) - yearly
- Measles, Mumps, Rubella - MMR
- Diphtheria, Tetanus, Pertussis (whooping cough) - Td, Tdap
- HPV-associated cancers and papillomas (warts) - HPV
- Meningococcal
- Hepatitis A and B

ADULTS (18 - 60 YR)

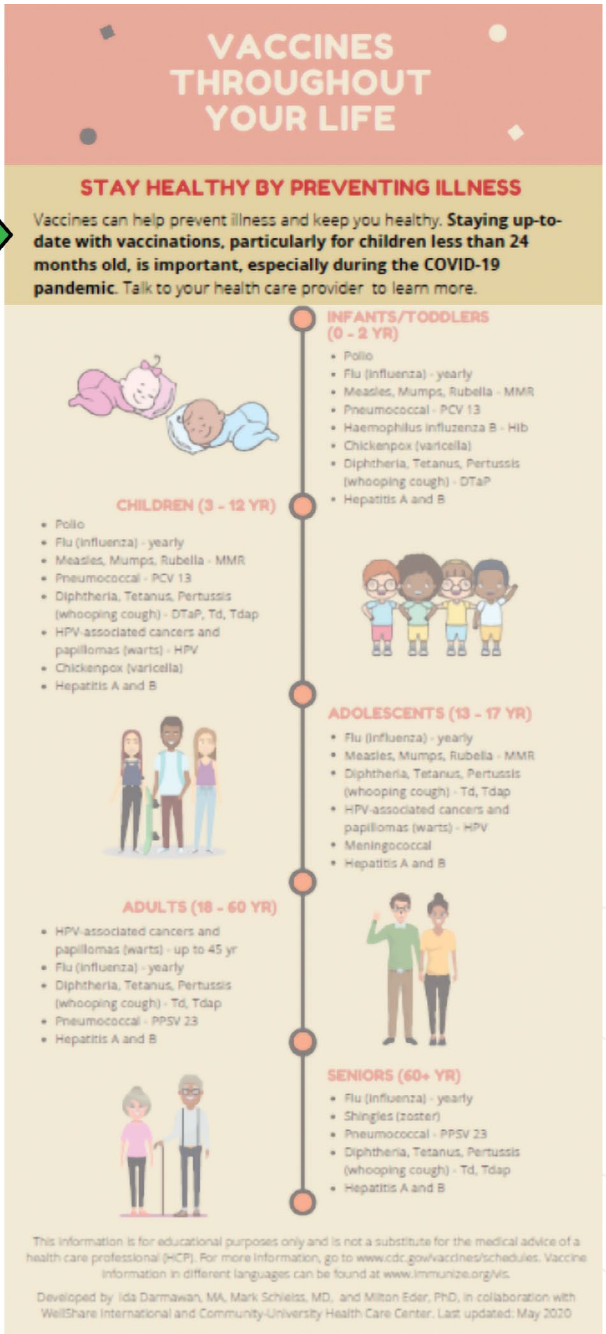
- HPV-associated cancers and papillomas (warts) - up to 45 yr
- Flu (influenza) - yearly
- Diphtheria, Tetanus, Pertussis (whooping cough) - Td, Tdap
- Pneumococcal - PPSV 23
- Hepatitis A and B

SENIORS (60+ YR)

- Flu (influenza) - yearly
- Shingles (zoster)
- Pneumococcal - PPSV 23
- Diphtheria, Tetanus, Pertussis (whooping cough) - Td, Tdap
- Hepatitis A and B

This information is for educational purposes only and is not a substitute for the medical advice of a health care professional (HCP). For more information, go to www.cdc.gov/vaccines/schedules. Vaccine information in different languages can be found at www.immunize.org/vis.

Developed by Ida Darmawan, MA, Mark Schleiss, MD, and Milton Eder, PhD, in collaboration with WellShare International and Community-University Health Care Center. Last updated: May 2020



VACCINES THROUGHOUT YOUR LIFE

STAY HEALTHY BY PREVENTING ILLNESS

Vaccines can help prevent illness and keep you healthy. **Staying up-to-date with vaccinations, particularly for children less than 24 months old, is important, especially during the COVID-19 pandemic**. Talk to your health care provider to learn more.

INFANTS/TODDLERS (0 - 2 YR)

- Polio
- Flu (influenza) - yearly
- Measles, Mumps, Rubella - MMR
- Pneumococcal - PCV 13
- Haemophilus influzenza B - Hib
- Chickenpox (varicella)
- Diphtheria, Tetanus, Pertussis (whooping cough) - DTaP
- Hepatitis A and B

CHILDREN (3 - 12 YR)

- Polio
- Flu (influenza) - yearly
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- Hepatitis A and B

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- Measles, Mumps, Rubella - MMR
- Diphtheria, Tetanus, Pertussis (whooping cough) - Td, Tdap
- HPV-associated cancers and papillomas (warts) - HPV
- Meningococcal
- Hepatitis A and B

ADULTS (18 - 60 YR)

- HPV-associated cancers and papillomas (warts) - up to 45 yr
- Flu (influenza) - yearly
- Diphtheria, Tetanus, Pertussis (whooping cough) - Td, Tdap
- Pneumococcal - PPSV 23
- Hepatitis A and B

SENIORS (60+ YR)

- Flu (influenza) - yearly
- Shingles (zoster)
- Pneumococcal - PPSV 23
- Diphtheria, Tetanus, Pertussis (whooping cough) - Td, Tdap
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Developed by Ida Darmawan, MA, Mark Schleiss, MD, and Milton Eder, PhD, in collaboration with WellShare International and Community-University Health Care Center. Last updated: May 2020

Example: Solano County Interdisciplinary Collaboration and Cultural Transformation Model (ICCTM) Innovations Project

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Background and Purpose

The Solano County Interdisciplinary Collaboration and Cultural Transformation Model (ICCTM) project was a 5½-year initiative to improve access to and use of mental health services. The ICCTM served Filipino American, Latino, and LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Queer/Questioning) communities. County staff members, members of community-based organizations, and communities have been key participants in planning, implementing, and evaluating the project.

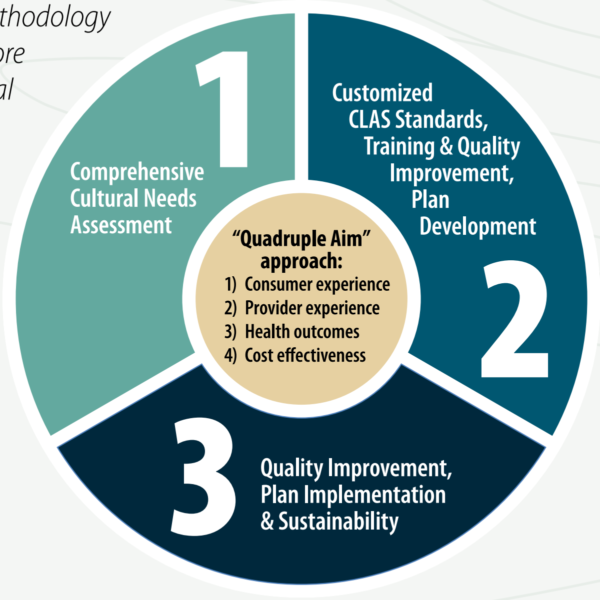
Partners completed the ICCTM project in 2021. Partners included Solano County Behavioral Health (SCBH), the UC Davis Center for Reducing Health Disparities (CRHD), the Community Engagement program of the Clinical and Translational Science Center, and three community-based organizations. ICCTM focused on key cultural and linguistic competencies required to highlight the experiences and mental health needs of underserved Filipino American, Latino, and LGBTQ+ communities of Solano County, California. These populations have lower access to and use of county mental health services. Traditional approaches to serve these population by providers were mostly based on their skill sets and involved limited community engagement efforts.

Methods

The ICCTM method was rooted in community engagement. It incorporated three phases aligned with the core values of the Mental Health Services Act (MHSA) and the SCBH/CRHD partnership (Figure 3.3).

Figure 3.3

Three Phases of Methodology Aligned with the Core Values of the Mental Health Services Act (MHSA) and the SCBH/CRHD Partnership



The first phase included a comprehensive cultural needs and assets/strengths assessment of members of the three communities of focus, cultural brokers, and community leaders. The second phase comprised a tailored training program and action plans based on the nationally recognized Culturally and Linguistically Appropriate Services (CLAS) standards called "Providing Quality Care with CLAS" (U.S. Department of Health and Human Services, 2023). The third phase focused on implementing and aligning the action plans to a delivery of care system that is culturally and linguistically appropriate and sustainable.

Results/Outcomes

The ICCTM intervention and implementation of action plans increased the average number of access line users from about 1,600 to 2,070. The number of callers increased 1.5-fold for Latinos and Filipino Americans, 5-fold for callers who identified as a gender other than "male" or "female," and 7-fold for callers who identified as other than "heterosexual." Data also suggested a shift from acute mental health care via crisis services to more preventive outpatient care in the Solano County Behavioral Health system. For example, there was a decrease of first admissions via crisis services of 15% for Filipino Americans, 8% for Latinos, and 8% for those identifying as LGBTQ+. Overall, the project showed that community engagement efforts, combined with community-defined strategies, improved the use of mental health services for the communities of focus. The Solano County Interdisciplinary Collaboration and Cultural Transformation Model (ICCTM) Innovation Project Final Evaluation Report is available at: https://health.ucdavis.edu/media-resources/crhd/documents/pdfs/icctm-final-report-2021-09-13.pdf. The Association of American Medical Colleges (AAMC) awarded the ICCTM Innovations project 2nd place in the 2022 "Innovations that Bolster Community Trust in Science Award."

Overall, ICCTM project was community-initiated, outcome-driven, and sustainability-guided. The project demonstrated that it is possible to address mental health disparities and advance mental health equity in access to care and use of services for historically underserved populations. Given the success of the ICCTM project, its funder, the Mental Health Services Oversight and Accountability Commission (MHSOAC), approved additional funds. MHSOAC awarded an additional $700,000 to scale up this project's strategies to 44 California Counties. A statewide learning collaborative was launched in July 2022 and included two one-year long training cohorts. The learning collaborative has since expanded to all 44 counties.

Application of the Principles of Community Engagement

The ICCTM project incorporated all 10 principles of community engagement. A 5½-year commitment to develop and implement long-standing plans to respond to the cultural and language needs of vulnerable communities speaks to Principle 9. Trustworthiness (Principle 10) was integral to create a support network among a county, university, community-based organizations, and three communities. This network created a sense of connection and inclusion.

Challenges/Lessons Learned

The following are four examples of lessons learned from the ICCTM project:

- Seek community involvement early in the process. Community members are cultural brokers and have lived/life experiences.
- Use community-identified resources and assets and integrate them as part of the solution.
- Be realistic and transparent with communities of focus about challenges and financial limitations of any project. This includes discussions about sustainability and innovation within a community engagement framework.
- Establish a consistent multidirectional communication structure from the beginning with all community partners. Set realistic expectations (roles and responsibilities), which are vital to sustaining relationships built on trust and trustworthiness.

Implications for Advancing Health Equity

Health and mental health inequities for historically underserved populations, including immigrants, have persisted for decades. A key question has been whether community-initiated and community-driven approaches can advance health/mental health equity with historically underserved populations. The ICTM project's outcomes positively answer that question. We provided evidence that the ICCTM model's interventions advanced mental health equity within the three communities of focus. The funders of the ICCTM project scaled the project up and funded a statewide Learning Collaborative. This collaborative provided one full year of workshops to other counties. Representatives of 44 California counties are engaged in the training. Training on the 10 principles of community engagement, including the new 10th principle, was part of the training workshops.

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Example: The Interdisciplinary Guided Network for Investigation, Translation and Equity (IGNITE), National Institutes of Health

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Supported by the Division of Engagement and Outreach, *All of Us* Research Program, National Institutes of Health, Award Number: OT2OD031915. *All of Us, the All of Us logo, and "The Future of Health Begins with You" are service marks of the U.S. Department of Health and Human Services*.

Background and Purpose

In 2015, United States President Barack Obama launched an initiative aimed at reducing health disparities: the Precision Medicine Initiative. The initiative is now known as the *All of Us* Research Program. The *All of Us* Research Program addresses disparities in precision medicine. Precision medicine focuses on individual variability as opposed to medically treating every person the same way. Disparities emerged because the majority of those participating in genetic and genomic medical research over the prior two decades identified as being European White in ancestry. Human beings are more genetically alike to one another than we are different. Where genetic differences are expressed, targeted diagnostics and treatments can be life-changing and lifesaving. It is equivalent to blood type. We are different from each other, although there are components of heritability. However, the *All of Us* Research Program is not based on the social construct of race. The program understands that race is a social construct rather than a biological one, and that social conditions influence health more than any other factor. The program seeks to capture the social, structural, and environmental drivers of health. The goal of the program is to reflect the rich diversity of the United States. This million-person plus research platform marries a wide assortment of data, including:

- Genomic data
- The social and vital determinants of health
- Electronic health records
- Data from wearables, such as smart watch data
- Physical measures
- Survey responses

Combined, these data provide a full picture of health over a decade or more.

The *All of U*s Research Program modeled community engagement from the start. Before program launch, the program involved 200 community groups. Previous studies had not intentionally focused on populations such as racial and ethnic minorities, LGBTQ+, disabled people, people without access to care, rural populations, older adults or pediatrics. However, the *All of U*s Research Program did. Previous studies grouped populations together in ways that could obscure data for minority sub-groups. Examples include combining all people of Asian ancestry into one group, or all LGBTQ+ populations together. The program encouraged distinctions across and between groups.

The *All of U*s Research Program pioneered a new paradigm of research by ensuring that those who donate their data to the study, known as "participants," are part of the process and represented in every phase of building the platform and program. The program also prioritized the training for, and recruitment of researchers underrepresented in the biomedical workforce as well as researchers at all career stages. The *All of U*s Research Program itself does not conduct studies. Rather, it provides an accessible but protected platform, curated data and a cloud-based analysis system in common programming languages for researchers at all levels, from high school students to community members to senior academics, to address minority health and health equity. For analysis, registered users who undergo increasing levels of security training and verification, can build cohorts within the data. The goal of such cohorts is to reduce health disparities, promote health equity, and advance our understanding of health and disease.

Methods

The main research program focused on an ecological model that included engagement at each level. In addition to the main program, the National Institutes of Health (NIH), *All of Us* Research Program, Office of Engagement and Outreach further funded studies to bring diverse researchers to the research platform. The NIH funded the Interdisciplinary Guided Network for Investigation, Translation and Equity (IGNITE) to bring community researchers and others underrepresented in the biomedical workforce to the data browser and Researcher Workbench. We use the term data to indicate the information in the data set of the *All of Us* Research Program. NIH developed IGNITE to demonstrate how community organizations can use this data to improve community health. In addition, IGNITE's innovative Data Picnic, Data Sandbox, and Data Playground models can introduce community and specialty groups to the data set. These models can help community organizations analyze the data to return value to communities.

Data Picnics introduce small groups of 8-10 scientists with related interests to the *All of Us* Researcher Program Researcher Workbench. Data Picnics guide these small groups in discrete exercises to produce analysis for a specific project, pilot data for a study, or background data for a publication.

Data Sandboxes convene large groups of 20–40 people who share a common interest or occupation. For example, these groups could include a group of community organizations, professional groups such as social workers or nurses, middle and high school teachers, Department of Health employees, and non-traditional researchers such as journalists. After a short introduction to the free and open-source data set, Data Sandbox participants work in pairs to complete a tailored data "treasure hunt." The treasure hunt includes questions that reflect the group's specialty. In other words, social workers have 20 questions related to the social determinants of health. Nurses have the opportunity to find information about nurse-sensitive indicators. Journalists learn how to use the data set to combat misinformation (correlation does not equal causation). Community researchers learn how to get information about conditions in the communities they serve.

Data Playgrounds are known as Tailored Outreach for Uniting Community Health; or TOUCH Playgrounds). This model uses a four-step model provide community-led health programming:

1) **Investigation**
2) **Education**
3) **Evaluation**
4) **Invitation (link to local services)**

We usually conduct Data Playgrounds at community and church health fairs and Safe Streets activities. We help community organizations identify the top three medical conditions of their communities by:

- Using the *All of U*s Research Program data set
- Providing infographics from reliable health websites (i.e., CDC, NIH) in appropriate languages
- Arranging for students in the health professions, nurses, podiatrists, dentists, and medical students to provide community education
- Working with hospitals and health systems to provide point-of-care testing and screening and linking participants to local services.

Working with NIH and program leadership, IGNITE embarked on a year-long set of national convenings to solicit community input on the program's scientific roadmap. IGNITE also directly funded community organizations with grants of up to $50,000 in NIH funding to enhance their work and better understand how the data could help improve community health. IGNITE projects included:

1) **A wellness clinic in New York City Public Housing in New York with activities guided by the data**
2) **The creation of a tailored Spanish Community Health Worker Curriculum to address the community's primary concerns in the Bronx, Brooklyn, Queens and Manhattan in New York**

Results/Outcomes

After attending a sandbox or picnic event, participants felt engaged and empowered through research. Participants included:

- Community members
- Nurses
- Social workers
- High school students and high school teachers
- Journalists
- Employees of the New York City Department of Health

About 96% of 550 participants felt that the training programs met their specific needs. After attending a workshop, participants said they knew more about the data set and the potential for work that could improve their community health than they had known before. Community scientists, front-line health care providers and community health workers felt that having access to a data set brought a dimension and perspective to their work and made them feel valued. Working with this diverse and powerful data set helps to democratize data access for educational institutions and community and local organizations. This includes high schools, public and community colleges, and teaching-intensive (as opposed to research-intensive) colleges and universities. The educational institutions and community and local organizations would not have access to such data without curation and support from the National Institutes of Health.

Applications to Principles of Community Engagement

The NIH, under a supplement to co-author Dr. Cohn, brought 200 community members and representatives of community organizations to Bethesda, Maryland for a listening session. This session occurred before the national launch of the program, while it was still in development. The 200-member delegation included the family of Henrietta Lacks.[2] The Lacks family continues to consult with program leadership nearly a decade into the study. Before launch, the *All of Us* Research Program developed Participant and Community Ambassadors' Boards. The program developed the boards for both the national program and at each enrollment site. The program also developed dedicated engagement counselors. The program collaborates with hundreds of communities and local organizations across the nation to support outreach and engagement initiatives though Pyxis Partners and the *All of Us* Research Program's Division of Engagement and Outreach.

Lessons Learned

Using the data collected to improve community health heightened communities' appreciation of research and how it can return value. Researchers supported community-led research teams who were guided by their own concerns in using data to answer their own questions. Through IGNITE, the program employs two biostatisticians trained in community work. Future plans include a national program for community-engaged biostatisticians who will employ community engagement tools and frameworks to deepen data use by communities and for communities (Richmond et al., 2024).

Figure 3.4 IGNITE Staff Elizabeth Cohn and Nakisa Pourkey in a Data Playground in Harlem New York.

Image taken by Bruce Cohn, 2022.

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[2] Henrietta Lacks was a mother of five who was treated for cervical cancer at Johns Hopkins Hospital in 1951. Her cancer cells were used for cancer research. Named "HeLa" cells, the cells are used to this day to study a variety of effects, such as from drugs and viruses, on the growth of cancer cells (Johns Hopkins Medicine, 2024).

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Example: The Helping to End Addiction Long-term® Initiative, or NIH HEAL Initiative®

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Background and Purpose

The public health crisis of opioid misuse, addiction, and overdose in America continues to rapidly evolve. The crisis reflects the fact that pain and addiction, often combined with mental illness, are complex conditions. Prevention and treatment strategies that are safe and effective and resonate with people living with these conditions have not been adequately addressed. In 2022, more than 107,000 Americans lost their lives to drug overdoses. More than 80,000 of those were from opioids, including highly potent synthetic opioids like fentanyl (National Institute on Drug Abuse, 2024). During 2021, 50 million Americans experienced chronic pain, or pain that lasted three months or longer. An additional 17 million experienced high-impact chronic pain, meaning pain that limits the ability to work, tend to daily activities or socialize (Centers for Disease Control and Prevention, 2023).

Many people may rely on opioid medications for their pain, and some may become addicted. Decades of research show that addiction is a disease of the brain that creates an uncontrollable need to continue to take drugs even when they cause harm to oneself or others. Opioid addiction is treatable. However, only a fraction of people who could benefit from effective treatments get one of the three U.S. Food and Drug Administration-approved drugs for treating opioid use disorder (e.g., methadone, buprenorphine, and naltrexone) (Centers for Disease Control and Prevention, 2024).

Barriers to treatment include:

- Persistent, widespread stigma
- Uncoordinated care
- Social (e.g., housing) barriers

These barriers to treatment contribute to the lack of access and limited use of the medication solutions. For specific types of pain, such as chronic lower back pain, many alternative strategies are effective, such as mindfulness-based therapy and yoga. Yet most people who could benefit from these complementary and integrative care approaches do not receive them. HEAL researchers are working diligently to address these intertwined public health challenges.

Methods

In 2018, the National Institutes of Health (NIH) launched the Helping to End Addiction Long-term (HEAL) Initiative, or NIH HEAL Initiative. The initiative provides scientific solutions to the evolving crisis of undertreated pain and opioid misuse, addiction, and overdose. To conceive HEAL, NIH pursued a yearlong consultation with patients, advocates, academic experts, private sector leaders, and federal partners to identify the greatest needs and areas of opportunity. The program is a trans-agency research effort. It focuses on improving prevention and treatment for opioid misuse and addiction and enhancing pain management. With dedicated support from the United States Congress, as of July 2023, HEAL has funded more than $2.5 billion in research through more than 1,000 projects nationwide. HEAL plans to expand research investments. This comprehensive approach includes efforts to:

- Develop more effective therapies for managing pain and for treating opioid use disorder
- Test effective pain management strategies that limit addiction risk
- Put into place evidence-based addiction treatment in a variety of settings

HEAL spans the entire research lifecycle from basic science to implementation research. It benefits from untraditional yet productive partnerships between communities, scientists, government, and the private sector.

Results/Outcomes

To achieve its goals, HEAL centers its efforts around four cross-cutting themes:

- Using a whole-person/patient-centric approach, working with communities to bring research to life
- Targeting the biology of pain and addiction
- Addressing health system challenges and inequities

In addition, the initiative places a high priority on transparency because open science and maximal data sharing are critical for applying scientific solutions to an evolving crisis. HEAL empowers researchers to make their HEAL-generated data FAIR (findable, accessible, interoperable, and reusable). The HEAL Data Ecosystem enables HEAL data to be searched, analyzed, and used by scientists, advocates, clinicians, and community organizers. To date, significant HEAL research findings have emerged from the initiative. These include a new standard of care for infants born dependent on opioids and patient-specific chronic pain brain signatures. These also include established safety for using buprenorphine in hospital emergency departments in the era of fentanyl and reduced recidivism among incarcerated individuals who receive addiction treatment.

Applications to Principles of Community Engagement

Both pain and addiction are conditions that are not well addressed by the U.S. health care system. For this reason, HEAL considers the voice of individuals with lived experience vital. Decades of stigma, discrimination, and fragmented care necessitate developing scientific solutions that are practical, durable, and patient-friendly. A core HEAL principle is that research must be relevant to the individuals, families, communities, and populations that it tries to help. HEAL's whole-person research approach recognizes that individuals are unique. Individuals have a range of conditions and experiences that affect resilience and risk. Communities across the country are highly diverse. Such diversity requires culturally relevant approaches that resonate with the communities. Patients and the people who care for them, families and friends, and community groups who provide support all have valuable insights into guiding meaningful research. HEAL scientists take a variety of unique approaches to incorporate guidance and perspectives of community members into their research projects. These efforts develop through the context of individual studies, settings, and patient populations. Such efforts enhance the engagement of patients, communities, and other partners. They also improve recruitment, retention, and inclusion of participants from populations that experience health inequities. The HEAL Community Partner Committee, convened in 2021, aims to help HEAL identify, refine, and prioritize patient and community engagement activities. HEAL-funded research involves people with lived experience throughout the research process. People are involved in planning a study, implementing it, and sharing the results so they can be helpful for real people in real communities.

Chapter Conclusion

This chapter provides examples of successful community engagement projects in a variety of communities and settings. These settings include academic health centers, community-based organizations, churches, and the public health sector. All featured projects followed some or all of the 10 principles of community engagement. The literature details many other successful efforts. However, the literature less often examines the organizational capacities required to make these efforts successful.. The next chapter, Chapter 4, addresses the organizational support necessary for effective community engagement.

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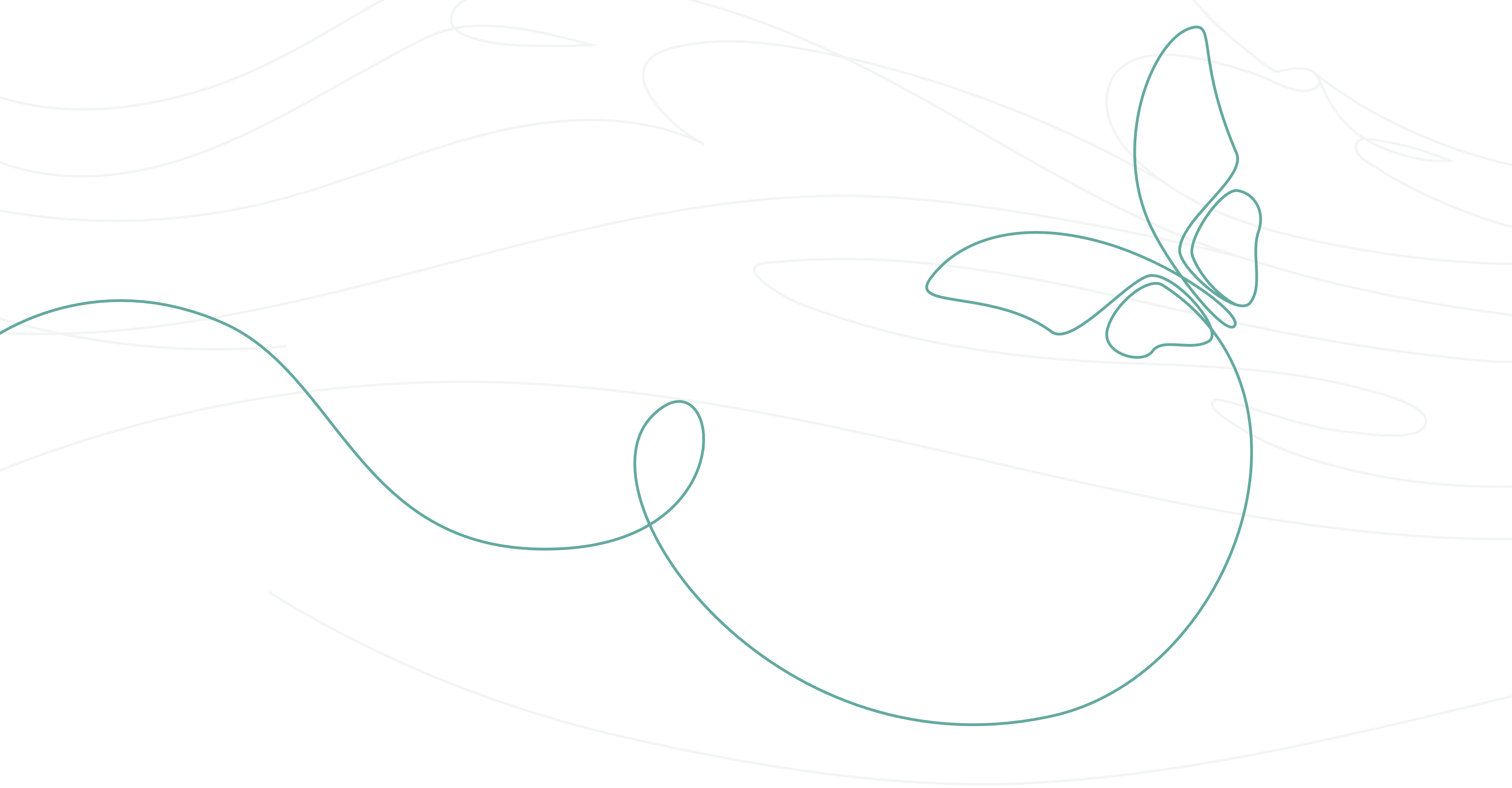

Appendix 3: Accessible Descriptions for Complex Graphics

Figure 3.1—Linguistic Decentering

Figure 3.1 is a chart containing steps of linguistic decentering, such as using different words to say the same thing in two languages. The authors use the concept of Science Café led by a University of Minnesota and WEllShare International research team. The team includes community and public attendees along with community health workers.

The first step is priority topics identified. In this step, community health workers host and observe Science Cafés and compile their observations. Attendees participate in the Science Café and complete self-assessments.

The whole group's next steps are to identify decentering opportunities and to test decentering opportunities in communities. Then, the group will implement and disseminate results. In addition, during these steps, the research team will provide feedback to presenter after each of 3 cafés.

◀ *Return to Figure 3.1*

Figure 3.2—Vaccine Infographics

Figure 3.2 shows two vaccine infographics that demonstrate linguistic de-centering. The infographics are titled "*Vaccines throughout Your Life*". The infographics are nearly identical. Both Infographics have the sub-title Preventing Illness.

The first infographic states, "Vaccines can help prevent illness and keep you healthy. Most vaccines are given only once in your life, some are given multiple times. Talk to your health care provider to learn more about vaccines."

The second infographic states, "Vaccines can help prevent illness and keep you healthy. Staying up-to-date with vaccinations, particularly for children less than 24 months old, is important, especially during the COVID-19 pandemic. Talk to your health care provider to learn more."

Then, both infographics have an identical vertical timeline with vaccines needed at different stages of life and images of people at those different stages. These are:

- **Infants/toddlers (0 to2 years)**
  - Polio
  - Flu (influenza)—yearly
  - Measles, Mumps, Rubella—MMR
  - Pneumococcal—PCV 13
  - Haemophilus influenza B -HiB
  - Chickenpox (varicella)
  - Diphtheria, Tetanus, Pertussis (whooping cough)—Dtap
  - Hepatitis A and B
- **Children (3 to 12 years)**
  - Polio
  - Flu (influenza)—yearly
  - Measles, Mumps, Rubella—MMR
  - Pneumococcal—PCV 13
  - Haemophilus influenza B -HiB
  - Chickenpox (varicella)
  - Diphtheria, Tetanus, Pertussis (whooping cough)—Dtap, Td, Tdap
  - HPV-associated cancers and papillomas (warts)—HPV
  - Chickenpox (varicella)
  - Hepatitis A and B

- **Adolescents (13 to 17 years)**
    - Flu (influenza)—yearly
    - Measles, Mumps, Rubella—MMR
    - Diphtheria, Tetanus, Pertussis (whooping cough)—Dtap, Td, Tdap
    - HPV-associated cancers and papillomas (warts)—HPV
    - Meningococcal
    - Hepatitis A and B
- **Adults (18 to 60 yeasr)**
    - HPV-associated cancers and papillomas (warts)—HPV
    - Flu (influenza)—yearly
    - Diphtheria, Tetanus, Pertussis (whooping cough)—Dtap, Td, Tdap
    - Pneumococcal—PPSV 23
    - Hepatitis A and B
- **Seniors (60 plus years)**
    - Flu (influenza)—yearly
    - Shingles (zoster)
    - Pneumococcal—PPSV 23
    - Diphtheria, Tetanus, Pertussis (whooping cough)—Dtap, Td, Tdap
    - Hepatitis A and B

Both infographics state that the material is for educational purposes and is not a substitute for the medical advice of a health care professional (HCP). For more information, go to https://www.cdc.gov/vaccines/imz-schedules/index.html. Vaccine information in different languages can be found at www.immunize.org/vis.

◀ *Return to Figure 3.2*

Figure 3.3— Three Phases of Methodology Aligned with the Core Values of the Mental Health Services Act (MHSA) and the SCBH/CRHD Partnership

Figure 3.3 shows a donut-shaped image. In the center, it states "Quadruple Aim" approach:

1) Consumer experience
2) Provider experience
3) Health outcomes
4) Cost effectiveness

There are 3 phases of methodology that intersect the Quadruple Aim approach:

Phase 1 — Comprehensive Cultural Needs Assessment
Phase 2 — Customized CLAS standards, training and quality improvement, plan development
Phase 3 — Quality improvement, plan implementation and sustainability

◀ *Return to Figure 3.3*

CHAPTER 4: BUILDING AND STRENGTHENING ORGANIZATIONAL CAPABILITIES FOR COMMUNITY ENGAGEMENT

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Community engagement is an ongoing and evolving process of multidirectional collaboration. Such collaboration occurs with and for people to solve problems and mitigate concerns that matter to them through durable and equitable relationships. The ultimate goal is to create or enable services, policies, programs, and practices to improve health and increase empowerment in the community (Aguilar-Gaxiola et al., 2022). Community engagement is critical for addressing health inequities and enhancing inclusiveness in health care and research (O'Mara-Eves et al., 2015). Building capabilities within organizations for meaningful community engagement is therefore an essential part of system-level strategies for building healthy communities and redressing historical social injustices. Such injustices include structural racism, and their resulting social, mental, and physiological effects. Advancing this goal requires commitment to improving health in communities by organizations across all relevant social determinants of health.

Community engagement requires a group of complementary partners who share a purpose and capitalize on their diversity and collective assets to foster the exchange of ideas, knowledge, skills, and resources (Bergeron et al., 2017; Matus et al., 2018; Parent & Harvey, 2009). This approach is akin to communities of practice or communities of solutions (Graham et al., 2016). Bringing together individuals from within both organizations and the community who represent a variety of professions, cultures, perspectives, skills, knowledge, and experiences can help establish goals deemed relevant and attainable by all partners, as well as other community and organization partners (Liberato et al., 2011). Shared goals in community engagement promote the quality and reach of the collectively implemented activities.

However, there are potential pitfalls and risks when partners implement engagement activities with poor fidelity to best practices. The commitment and readiness for community engagement vary considerably across those who wish to partner with community organizations. We define organizations as academic health centers and other accredited training institutions, private industry, pharma, universities and colleges, and sectors and institutions other than community-based organizations. Equitable partnerships as envisioned for community-engaged research are difficult to realize in town-and-gown academic-community relationships. We attribute this to traditional organizational cultures with limited understanding of community engagement principles. The implication is that academic and private sector organizations seeking to improve health in the community need capabilities in community engagement and partnerships to help them achieve long-term, meaningful impact in communities (Hawe, King, Noort, Jordens, & Lloyd, 2000). This requires an organization to strive to continually develop, leverage, and adapt its relevant human, informational, material, and financial resources to build infrastructure, foster capacity for problem-solving, enhance sustainability of activities (Liberato, Brimblecombe, Ritchie, Ferguson, & Coveney, 2011), and ultimately, create and sustain fruitful partnerships with communities.

This chapter presents an overview of how organizations may assess and build on their readiness to engage in community partnerships to achieve a meaningful impact. Figure 4.1 is a conceptual model for evaluating community-academic partnerships based on previously published models for community-based participatory research partnerships (Ward et al. 2018; Schulz et al., 2017; Heller et al., 2014; Schulz et al., 2003). Although we emphasize capabilities for academic health centers and other accredited training institutions, the guidance provided pertains to community, government, private, industry, and other organizations.

Figure 4.1 Conceptual Model for Evaluating Community-Academic Partnerships

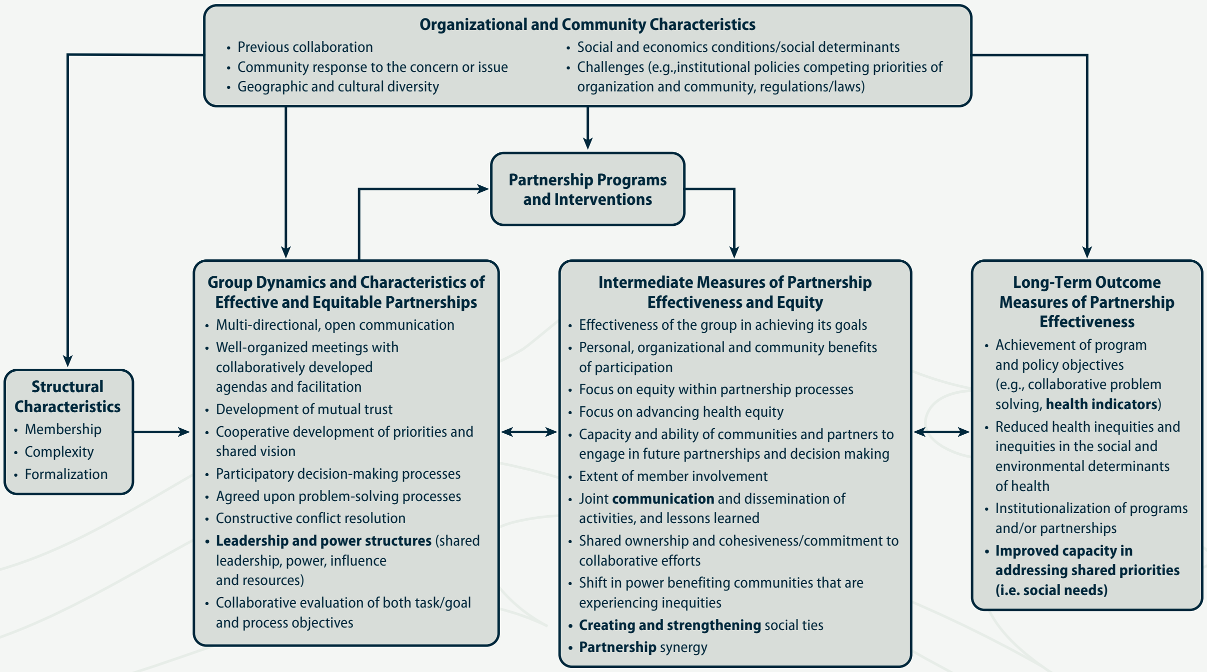

Figure 4.1 is an adaptation of a Conceptual Model for Evaluating Equity Within the Context of Community-Based Participatory Research Partnerships (Figure 1), in Ward et al., 2018. Ward et al. created their model based on work of Schulz, Israel, & Lantz (2003, 2017), Israel et al., 2013, and Heller et al., 2014. The bold text in the figure represents the main adaptations (Ward, et al., 2018).

Benefits of Community Engagement to Organizations

Community engagement offers benefits for organizations, including preparing a foundation for educational, clinical, and research activities in academic health centers and public health schools. It is integral to participatory and experiential pedagogy (also referred to as critical-service learning) on community-based experiences for learners (Mitchell, 2013). In recent years, attention to addressing health inequities and societal injustices has led to growing interest in community engagement (Tai, Shah, Doubeni, Sia, & Wieland, 2021). For instance, community engagement became a key part of the national strategies for promoting inclusive research and addressing disparities emanating from the COVID-19 pandemic (Gilmore et al., 2020; Ignacio et al., 2022). Community engagement enables organizations to co-create initiatives with communities so that the tools or approaches are culturally aligned with community values, preferences, and priorities. Also, national organizations have developed health equity measures for inclusion as part of the criteria for the annual national ranking of hospitals in the United States. Organizations with regulatory requirements, such as the Affordable Care Act mandate for non-profit hospitals to conduct periodic community health needs assessments, benefit from integrating community engagement as a core component of such activities.

Overall, experience shows that investment in community engagement can increase readiness for national and local crises such as the COVID-19 pandemic (Bollyky et al., 2022; Brewer et al., 2020; Brewer et al., 2021; Gilmore et al., 2020; Wieland et al., 2020). Investing in community engagement can:

- Support and improve performance metrics for organizations
- Improve conditions for employees who live in those communities
- Create opportunities to leverage partners' resources.

Organizations that commit to long-term and sustained community engagement may accrue the most significant returns.

Frameworks for Building on and Strengthening Capabilities

Community engagement capabilities encompass knowledge, skills, networks, culture, leadership, training, commitment, data, policies, systems, space, and funding for community engagement-relevant activities. There several organizing frameworks for building on and sustaining capabilities for organizations in community-engaged partnerships, including:

- The principles of community engagement (Chapter 2)
- The Community Coalition Action Theory (Frances Dunn Butterfoss, 2007; Frances D Butterfoss & Kegler, 2002)
- The Constituency Development framework (Hatcher MT, 2008).

Irrespective of the framework or principles used, the ideal is a playbook or guidance for organizational leaders to create capabilities and shape cultures that promote meaningful, synergistic partnerships in communities. Box 4.1 presents an overview of principles of partnership synergy.

BOX 4.1 Guiding Principles of Partnership Synergy

1) Demonstrate trustworthiness.
2) Adopt transparent multidirectional communication processes.
3) Value existing community capacities.
4) Promote inclusive leadership and decision-making processes.
5) Train the workforce to build a 'critical mass' of community engagement expertise.
6) Assess organizational readiness and preparedness.
7) Evaluate and adapt to achieve sustainability.

Partnership Synergy is a marker of a successful collaborative process. It is created when partners recognize, value, and blend their complementary knowledge, perspectives, resources, skills, and other assets to achieve more than the sum of what each partner could achieve alone (Lasker, Weiss, & Miller, 2001). Thus, the problem-solving capacity of a synergistic partnership leads to solutions that the various partner groups consider relevant and are likely to use (Jagosh et al., 2012; Loban, Scott, Lewis, & Haggerty, 2021). While there is no one prescriptive formula for developing and sustaining partnership synergy, there are a set of broad guiding principles for organizations (see Box 4.1, Figure 4.1, and Practice Elements) that encompass its determinants, processes, and outcomes (Lasker et al., 2001; Loban et al., 2021; Wallerstein, Duran, Oetzel, & Minkler, 2017).

Trust is central to synergistic partnerships (Jagosh et al., 2012; Wallerstein et al., 2020). Trust develops and is nurtured through a continuous, dynamic process of affirming and reaffirming mutually positive intents and actions (Ahmed, 2020). In community-organization partnerships, the community needs to be confident that organizational partners have a genuine interest in focusing on relevant issues, will follow through on their commitments and responsibilities, and will not take advantage of them (Hoekstra et al., 2020; Jagosh et al., 2015; Ortiz et al., 2020). For instance, to demonstrate a commitment to collective goals, organization partners can offer training to the community. In the training, they can provide such resources as administrative, managerial, or technical support. Additionally, organizational partners need to be knowledgeable about the community and demonstrate recognition and value for community assets. They must be flexible, honest, transparent, forthcoming, respectful, humble, and willing to share decision-making or cede control to community partners. Co-developing a Terms of Reference document that addresses partnership procedures and partners' expectations, rights, and obligations is useful to build relationships and lay a foundation for trust.

A leadership process within the partnership that is inclusive and that fosters shared transparent communication, decision-making, trust, and respect is essential for a synergistic partnership to flourish. Such leadership helps to avoid misunderstandings. It allows partners to discuss shared goals and differences openly. It enables them to work through tensions and recognize and combine their respective assets for greater impact. Strategies include (Figure 4.1):

- Beginning partnership meetings by summarizing discussions and decisions of the previous meeting
- Clarifying goals of the current meeting
- Continually checking for shared understanding among partners regarding objectives, tasks, and expectations

Regular evaluation to assess partnership progress and functioning (Figure 4.1) is important to build community-organization partnership synergy. This synergy manifests itself in the capacity to adapt to the evolving context of engagement efforts (Loban et al., 2021), which is key to sustainability (Aluttis et al., 2014; Shediac-Rizkallah & Bone, 1998). Initially, a readiness assessment, as outlined under the Practice Elements, can clarify an organization's capability to implement change. The assessment can also identify areas in need of improvement. Ongoing monitoring and evaluation of the partnership and its activities can be a standing point on meeting agendas. Sharing results within the partnership helps partners recognize the benefits of their partnership and identify achievements.

Practice Elements for Developing Organizational Capabilities

The Constituency Development framework considers the process of developing relationships with community members who benefit from or have influence over community actions. The framework is based on defined practice elements (Hatcher & Nicola, 2008). We have used these elements to further organize this overview of the institutional organizational capabilities required for community engagement. The practice elements include:

1) **Understand and Assess Your Own Organization's Capabilities and Readiness**
2) **Understand the Community**
3) **Establish Positions and Strategies**
4) **Build and Sustain Networks**
5) **Adopt Collaborative Action**

We focus deeply on the practice element of organizational capabilities and readiness. Without this strong foundation, we cannot implement the four additional practice elements.

Practice Element 1: Understand and Assess Your Own Organizational Capabilities and Readiness

Each institution or organization has capabilities and limitations, as well as history and reputational considerations around community engagement—both internally and with community partners (Table 4.1).

Organizational self-awareness about community engagement capabilities includes meaningful and multidimensional self-assessment. Such assessment is both a first step and an ongoing quality improvement process. Part of self-assessment is gaining self-awareness of power differences that exist and the potential for institutional culture to become a barrier to forming relationships. Organizational history and reputation may seem separate from capabilities. However, it is common for community members to remember an institution's broken promises or history of practices that do not conform to community engagement principles for years (even decades). This can limit later engagement efforts. Organizational assessment encompasses several domains (Castañeda et al., 2012; Dearing & Singhal, 2020; Helfrich, Li, Sharp, & Sales, 2009) and should include:

1) **Tangible (e.g., human, financial, infrastructure) and intangible (e.g., culture, attitudes, history) resources belonging or accessible to an organization.**
2) **Management and governance systems, structures, and processes (e.g., strategic management, organizational structure, and evaluation).**
3) **Relationships and communication with external partners, potential partner organizations, and other partners.**

Table 4.1 Examples of Areas of Organizational Capabilities for Community Engagement

DOMAIN	SAMPLE ELEMENTS
Human resources	Requires competencies in leadership, management, community health, intervention design, and disciplinary sciences. a. Community engagement leadership: principles and practice, change management, and creating internal and external alignments across cultural boundaries b. Develop and sustain a critical mass of trained and empowered workforce members from beginners to advanced practitioners. This workforce should be versed in community engagement and related areas, including mixed methods, ethnography, program evaluation, and implementation science. c. Build and sustain relationships, coalitions, and networks. • Outreach, relationship-building, data collection and analysis, and information development and presentation • Technical assistance and assessment of training needs for organizational formation, planning and implementation of initiatives, communication and networking, and other engagement processes • Situational analysis and identifying opportunities for meaningful engagement
Organization resources	Organizational units; administrative, management, and service delivery structures; coordinating structures; communication channels and networks; regulatory or policy processes; and organizational and professional practices and processes.

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Table 4.1. continued

DOMAIN	SAMPLE ELEMENTS
Physical and financial resources	Real and perceived economic resources devoted to community engagement. This includes funding, workspaces, hardware, supplies, materials, and tools. a. Personnel, contract, or budget for community engagement-related activities b. Office space for staff members and to support community meetings c. Information technology support d. Electronic hardware and software and other digital resources and artifacts e. Technology and information and data systems to collect, manage, store, analyze, and report in desired formats for community partners f. Technical assistance and support training needs for partners for program implementation and evaluation g. Development and maintenance of communication channels and networks
Organizational culture	Organization's mission and culture of corporate citizenship and inclusive practices. a. Organization's mission or values statement that supports a culture of long-term engagement with community partners b. Recognition and reward systems for community engagement c. Leadership alignment d. Policies and procedures regarding collection, storage, release, or publication of information, along with privacy and security safeguards

Human Resources for Community Engagement

A key component for capacity is enough frontline staff members, managers, and specialized roles such as faculty or executive leadership with expertise in the principles and practice of community engagement. This includes human capital with knowledge of both conceptual frameworks and practical components of community engagement for real-world settings. Case studies and other problem-based learning strategies can assist learners in seeing theoretical aspects of community engagement in actual practical examples. Case studies can also illuminate successful and unsuccessful partnership strategies (Doubeni et al., 2022).

Workforce and Training

A strong training infrastructure can enhance readiness for community engagement. Training staff who do community engagement equips them to partner with the community, to advance partnership synergy, and to maintain alignment of purpose within an organization. Training includes skills in areas such as leadership, communication, and advocacy. Training also includes skills in consensus building, group facilitation and mediation; networking, community mobilization and partnership building; and project management, research, and evaluation (Bergeron et al., 2017; Lasker et al., 2001). Investing the time and resources for staff to develop synergistic partnerships with community advocates and collaborators is a crucial strategic management decision that can enable all partners to develop shared knowledge and skills. The training tools or approaches can be considered across several dimensions (Doubeni et al., 2022):

1) **Self-directed training** (e.g., online modules) on general concepts and approaches on community engagement may be sufficient for beginners and people not routinely performing community engagement. This training should include inclusive language and culturally appropriate practices. This would prepare them for informed interfaces with other people routinely involved in community engagement activities. The training and awareness can also help employees with personal interest or aptitude for community engagement to pursue more advanced and applied engagement work.

2) **Formal training** can focus on community engagement principles and practice, including topics on community-based participatory research (CBPR), equity, and social determinants of health (Commission on Social Determinants of Health, 2008; Solar & Irwin, 2010; Tai et al., 2021). The training should also include understanding community capacity-building, and community engagement strategies, and examining issues encountered during community engagement activities.
3) **Experiential training** for staff involved in larger community engagement efforts or with ongoing management oversight of community engagement activities. This may include immersive learning experiences in ongoing community engagement activities.
4) **Advanced field-based practice**, which may include:
    a) intensive, supervised training with extended time horizons (e.g., postdoctoral training with mentoring) or long-term staff roles that require collaboration with key community partners and the expectation that the learner will increasingly manage their relationships independently (Meurer et al., 2020)
    b) advanced community engagement practitioners working with partnering organizations where ongoing training of learners, along with scholarly activities, occurs as a part of practice.

Develop and Sustain a Pool of Advanced Community Engagement Practitioners

Training can teach many community engagement skills. However, community engagement is also an art that requires the practitioner's personality and skills, which may take years of field experience. Practitioners should approach training as an endeavor of lifelong learning (Doubeni et al., 2022).

Training with graduated supervision and on-the-job learning within the framework of building and sustaining partnerships can develop advanced community engagement staff, faculty, and executives. Such training can manage the available workers over the long term. Seasoned community engagement practitioners forge enduring personal relationships with multiple partners, identify areas of common interest among partners, and identify problems that emerge in community contexts before a crisis occurs. Advanced community engagement practitioners are attentive to subtle elements of cross-partner communication. Such communication includes generating common language within partnerships to ensure that all parties share an understanding. Practitioners also attend to and help balance power differences. They ensure flow of information and fair management of funds and other resources within partnerships. They wisely use diplomacy to address concerns when they or their organization err in the eyes of community members or partners.

Advanced community engagement practitioners can take on both leadership and followership roles. This means that, at times, they actively guide the activities of a collaborative of multiple partners toward specific goals. At other times they follow the community leader, enabling external partners to lead, possibly providing material or reputational support. While following the community leader may seem somewhat passive, it is actually an active role to embrace in enabling change or co-creation. Also, community partners often report that the "mere presence" of institutional partners can create paths toward community-led action. Even after full development, advanced practitioners will benefit from opportunities to debrief and consult with more senior colleagues or their peers as the complexity of their work grows (Doubeni et al., 2022).

Build and Sustain Relationships, Coalitions, and Networks

Building and sustaining relationships is foundational to community engagement. Organizations may take one of two main paths toward maintaining an awareness of the external relationships held by their community engagement workforce. The paths are either a centralized process or a decentralized process. In fully centralized approaches, a single office or department in the agency manages all external relationships. Individuals seeking to collaborate externally gain access through this single entity, which provides a single point of contact for key relationships and a clear "relationship manager" in charge of navigating early-stage collaborations. Larger and more complex organizations often adopt a decentralized approach because of the challenges of "monitoring" relationship-building activities. Multiple overlapping projects, funding streams, and individual partners with different relationships between agencies are the norm in this context. Thus, even in this model, a central coordinating entity is desirable to assure cohesion.

While strategies may exist for describing, monitoring, and maintaining partnerships, the personal aspects of the relationships require ongoing attention. Relationships for multi-agency activities often go beyond the capability of any single organization. Research in areas such as disaster management has identified organizational structures to use when complex events emerge. This includes elements of empowerment that enable individual response to changing contexts. Similarly, the challenges related to addressing social factors that drive health require organizations to collaborate in ways that go beyond typical bureaucratic structures.

Personal relationships between key staff members across agencies may have the power to overcome the barriers to cross-sector collaboration. Thus, to understand what is possible in collaborative arrangements, organizations must understand who key relationship managers are and work with them effectively. As described in Chapter 1, community-based action is often coalition-driven.

Organizations are typically part of multiple coalitions and, in some cases, a coalition of coalitions. Coalitions range from formal organizations with funding and permanent offices to informal groups of like-minded people working together without a formal structure. Leaders within organizations may be unaware of where and how individual relationship managers function within coalitions. Developing insight into how an agency connects to coalitions is a fundamental aspect of managing organizational capabilities.

Informational Resources for Community Engagement

Understanding the community and networks of relationships is critical for making the most of assets in the community that may otherwise remain unused. Integrating data and information from many sources, including health care, can help inform community-based action. Community engagement partnerships can use public health surveillance data and other secondary data sources together with targeted primary data collection to provide key insights about community assets and organizational potentials and to identify gaps in current practices. Organization leaders, community members and partners must share information in an understandable way. Social network analysis (SNA)—discussed further in Chapter 6—can help visualize the many community relationships among individuals and organizations within and beyond coalitions (Franco et al., 2015).

Organizational Resources for Community Engagement

Human Capital Management. Beyond training for community engagement, there are other workforce capacity considerations. Among these are inclusive practices, as well as recruiting and retaining linguistically and culturally diverse staff members who share and understand the community context. A good practice is to align hiring with diversity goals of representation of people from the community. To do this, it is important to revise restrictive hiring policies such as excluding people who have a history of incarceration. It is also important to align position descriptions with community members' skills and interests. Advertising positions in places that take advantage of informal networks can identify candidates with community engagement skills and relationships in the community.

Agency-Based Services. Self-assessment of capabilities should include understanding what other partners may find valuable about an organization. Organizations may be better able to share with partners by having employee training programs; broadcasting messages through distribution lists; and outreach and collaboration on health, wellness, and educational programs.

Infrastructure. Agency or institutional rules, regulations, policies, and tools play an important part in community engagement. Traditional business processes or organizational cultures can create friction for partners and make interacting with institutional procedures troublesome or hard to navigate. Transforming policies and procedures to be community-aware (or "community friendly") can streamline interactions with other agencies and community members.

Contracting. Community engagement activities often involve managing funds, equipment, and other resources through established business practices. Contracting processes often delay payment or initiation of projects. This may be particularly challenging for smaller community-based organizations and individual community members who may need flexible and responsive processes. Providing administrative support and creating appropriate scaffolding for managing standard business practices for community engagement programs can enable collaboration with community members.

Digital Solutions. Digital health inequities became more apparent during the COVID-19 pandemic. The impact of the "digital divide" (the gap in digital equipment, usage or skills, and outcomes) may accelerate with increasing digitization of health care services (Cheng et al., 2020; Estacio et al., 2019; National Academies of Sciences Engineering and Medicine, 2016; National Telecommunications and Information Administration, 1999, 2020; Parker et al., 2018; World Health Organization, 2018). The digital divide compounds other barriers to care and contributed to COVID-19 pandemic- related and other disparities (Dorsey & Topol, 2016; Ramsetty & Adams, 2020). Developing the organizational capacity to enable digital equity should be integral to community engagement programs. Also, as community engagement activities become more complex, well-defined monitoring and tracking processes and analytics become increasingly important. This includes information technology and analytics, as well as visualization tools. While technology cannot replace the human element needed for collaboration, a lack of insight from gaps in information and analytics can create problems and missed opportunities. Integrating data sources on community engagement activities into a single data storage and dashboard reporting system, as well as creating digital archives of community engagement products or artifacts, can help get the highest use and return on investment (Ahmed et al., 2019).

Funding. Organizations that provide financial support for ongoing community engagement activities are at an advantage in maintaining partnership ties in periods of no funding. Local, regional, and national endowments that work closely as core community engagement organizations could provide ongoing support for important aspects of community engagement activities that are vulnerable to funding gaps. Initial funding can help via pilot grants for partnered research and early partnership grants to support planning and relationship-building, among other things. For more established partnerships, continuing funding at the end of a grant period can help in wrap-up, final reporting, and dissemination. Creating partnerships with funded centers (e.g., the CTSA program and National Cancer Institute-designated comprehensive cancer centers) is another approach for sustaining activities during gaps in funding.

Organizational Culture and Mission for Implementing Shared Vision

An organization's ability to use its capabilities in community engagement depends largely on its culture (Doubeni, 2021). Organizational culture can be seen in the mission of the institution and the behavior of its senior leadership. An organization's culture is critical to the sustainability of community engagement. Senior leadership needs to understand at least the basic aspects of community engagement. It is important to have organizational alignment regarding the mission, scope, and scale of community engagement. This understanding can take the form of support for work-related behaviors and needs of advanced community engagement practitioners. In addition, it includes the ability to understand and balance the needs of multiple external community relationships and coalitions.

Differing expectations on deliverables or measures and lack of internal alignment on the necessary flexibility and adaptability can negatively affect community engagement activities and is often apparent to community members. At another level, community engagement staff members are health ambassadors. They manage community expectations about payments, equity considerations, historical grievances, sensitive and potentially damaging information, and other issues. To be effective, community engagement staff members need to trust that the promises they make on the ground are honored. This requires that community engagement staff members and senior leadership be in frequent and regular dialogue on community processes, requests, perspectives, and concerns. They should also share successes and challenges to ensure ongoing internal alignment. An organization's capabilities for community engagement can be improved by regular, multilevel, and multidirectional communication about how the organization aligns with community engagement staff's strategic vision.

Institutionalization of community engagement requires practical strategies, ways of thinking, and orientation toward ongoing collaborative work across many partners that are integrated into the organization's mission, vision, strategic goals, and budget. To be an effective long-term endeavor, community engagement cannot solely depend on grants. Senior leaders can show full and robust support by:

- Creating supportive internal infrastructure
- Developing internal community engagement leaders
- Creating appropriate positions at different levels of the organization (including community engagement representatives on critical committees)
- Rewarding and motivating community engagement staff members
- Removing barriers for promotion, and providing professional recognition of advanced community engagement practice (Ahmed et al., 2017)
- Including community research and community engagement as part of the tenure process

Practice Element 2: Understand the Community

Practice Elements 2 and 3 require mobilizing the capabilities just discussed to achieve a goal. Just as it is important to carefully examine institutional culture, it is critical to develop a deep knowledge of the community of focus. To learn about the community, try to focus on its history, experiences, values, preferences, constituents, trusted messengers, powerbrokers, and capabilities. Such knowledge enables planning, implementation, and use of resources to achieve collaborative outcomes with community partners. Examples of information gathered and used in relation to community engagement principles emphasizes the need for:

1) **A wide range of data types**
2) **Trusted and secured data collection and sharing processes**
3) **Human skills and equipment to analyze and interpret data**
4) **Organizational processes to communicate the information and foster its use in decision-making**
5) **A culture that values community-engaged information gathering and use**

The process enables all partners to understand both assets and diverse viewpoints on community issues and appreciate the range of possible solutions to address them. If partners do not develop a shared understanding, it is difficult to move to a collective decision or action.

The individuals and groups from communities or organizations undertaking community engagement activities may require different types of data and/or data presentation formats. Understanding data is rooted in experience, social and cultural perspectives, and perceptions of influence. Most communities have multiple layers that require organized, collective ways to acquire and understand community information. Thus, organizations must approach how they get to know a community as an organizational function. Organizations must support community engagement activities with sufficient capacity to undertake this work collectively. They should consider multiple variables that influence health, including social, cultural, epidemiologic, behavioral, environmental, political, and other factors.

Organizations should also consider frameworks for action and evaluation (Bikomeye et al., 2021; 1999; Commission on Social Determinants of Health, 2008; Solar & Irwin, 2010; Tai et al., 2021). Factors measured to assess health and social inequities should include community health indicators, as well as disaggregated data on population groups of interest (Aguilar-Gaxiola et al., 2014; National Institute on Minority Health and Health Disparities, 2017; Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2030).

Assessing the multiple variables and factors that influence health will provide insight into possible targets for health actions, competing interests in the community, and potential perceptions of the organization's strategies. It is important to partner with the community in this process as early as possible and to ensure that the organization has the capacity to collect, analyze, present, and manage perspectives and strategies to result in a shared decision-making process. Building and maintaining the structural capacity to perform this work requires rigorous attention from engagement leaders.

Practice Element 3: Establish Positions and Strategies

Organizations need to establish the ability to agree on a collaborative vision regarding community health priorities and any elements in the organization's mission, culture, policies, or funding that will limit achieving that vision. Developing positions and strategies allows an organization to plan its role in the community engagement process effectively. It is critical to be clear about the organization's intentions and its ability to adjust and respond to the community's differing viewpoints and priorities.

Infrastructure is needed for communities to partner with institutions or larger organizations. Both parties must understand the community capacity and readiness to participate and to act. If the capacity does not currently exist, it may be necessary to help with capacity-building in the community as a step toward starting a program. If the community has capacity but is not ready to act, organizations can develop strategies to work with the community to understand its priorities and perspectives on issues identified. In doing so, the organization should talk with the community to understand community expectations and develop a shared vision or approach that maintains community ownership or co-ownership.

Practice Element 4: Building and Sustaining Networks

Another area of organizational practice is developing collaboration networks to support community engagement. Collaboration networks include establishing and maintaining relationships; communication channels; and exchange systems that promote connections, alliances, and opportunities to use resources among constituent groups (Nicola & Hatcher, 2000). This critical function dovetails with Centers for Disease Control and Prevention's essential public health services (Centers for Disease Control and Prevention, 2020). Effective community engagement networks need active communication channels, fluid exchange of resources, and energetic coordination of collaborative activities among network partners (Figure 4.1 and Table 4.1). Important components for success include having the structural capacity to do the following:

- Identify and analyze network structures (communication, power, and resource flow)
- Affiliate with trusted or trustworthy networks
- Communicate through trusted messengers across formal and informal channels to maintain information flow and assure coordination of activities
- Direct communications and resources to enhance agenda-setting processes within the community
- Establish, use, and monitor resource exchange systems that support network interactions and coordinated collaborative community work (Kozel, et al., 2006; Kozel, Kane et al., 2006; Kozel et al., 2003)

Practice Element 5: Collaborative Action

Community engagement involves mobilizing community members, constituencies, and other organizations. Mobilization involves moving communities through the process of dialogue, debate, and decision-making to gain the commitment of all involved to a common goal. Mobilization also involves determining who will do what and how it will be done; putting activities in motion; and monitoring, evaluating, adjusting, and reevaluating these activities. A key to this practice element is earning the trust needed for creating community partnerships. To this end, the engagement process must be honest, and expectations must be clear. Leaders in both the community and the engaging organization must commit to meaningful negotiations to resolve any salient issues.

Chapter Conclusion

Effective community engagement requires an ability and commitment to assessing, developing, and mobilizing organizational resources needed to foster and maintain trustworthiness within the community and among partners. Building and strengthening the capabilities for community engagement helps organizations leverage the diversity within communities to advance priorities identified by the community. Organizations should continuously assess their preparedness and impact in collaboration with community partners. Organizational leaders must provide ongoing attention to building and maintaining the structural capacity needed for community engagement. This includes the skills and systems to communicate and relate to people on a personal basis, knowledge and understanding of community power structures, and a collaborative approach to sustained change.

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This person is part of a group of local residents who are restoring former sharecropper homes in the Missouri Bootheel.
Lloyd DeGrane, 2019.

Example: Ocean View Growing Grounds: Turning a Reclaimed Brownfield into a Successful Community Garden Project

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Background and Purpose

The Ocean View Growing Grounds (OVGG) is located in a Southeast San Diego community of color. The OVGG is a reclaimed brownfield (a property with hazardous substances in the ground or groundwater) that now serves as an established community garden and food forest. The Global Action Research Center (ARC) agreed to reclaim this brownfield in partnership with UC San Diego's Bioregional Center for Sustainability Science, Planning and Design; the City of San Diego; and the owner of the brownfield site. Using the OVGG site as a platform, the Global ARC is co-creating with the community new ways of participation to improve food security and food justice at a neighborhood scale. New collaborative arrangements respectfully and authentically create equality among participants in public reasoning, policy, planning, decision-making, and leadership. Participants include residents, scientists, researchers, students, and experts/non-experts. The Global ARC developed the OVGG site with local neighborhood residents through conversations hosted at the garden. The site has two components: the Learning/Action Research Center and the Neighborhood Food Network (NFN).

The Learning/Action Research Center is a neighborhood green gathering place that houses the central garden and holds workshops and hands-on demonstration projects on growing food. The center also hosts informational sessions on nutrition and the use of seasonal vegetables. It is a place where science and residents come together. The topics and events are informed by the specific needs and wants of visitors from the neighborhood.

The NFN is a network of resident property holders/owners and people interested in growing food. A survey revealed that a significant portion of the neighborhood was already growing food on their properties, which resulted in the network. The NFN expanded the OVGG capacity to produce fruits and vegetables by creating and supporting gardens on properties scattered throughout the neighborhood. The NFN gathered the food produced at the OVGG and NFN gardens and distributed it to members of the OVGG, allowing residents to enjoy a wider variety of harvests.

Methods

OVGG developed through a community engagement process that surveyed residents' interest and potential support for the establishment of a community garden and Learning/Action Research Center. Residents designed the layout of the site and provided outreach to their neighbors. The project incorporated a communal model. Residents participate collectively on specific days, complete gardening tasks, participate in planning, and share in the harvest, at no cost to themselves. This model builds a hub for social capital in their neighborhood that revolves around increasing access to fresh fruits and vegetables, as well as ways of living a healthier lifestyle. Consequent to this, partners from the Global ARC and Bioregional Center for Sustainability Science, Planning and Design collectively sought funding to build stronger connections between the campus and community. With this expansion, partner faculty brought students from various courses to OVGG to learn and contribute labor to building the space. Through this experiential, place-based learning, students gained a deeper understanding of the structural and health burdens facing local residents. They also experienced the power of co-creating a regenerative neighborhood center rooted in health, food, justice, and learning. In many cases, students worked alongside community members of all ages. The students had conversations and gained insights that provided real-world examples of theoretical classroom lessons about "bidirectional learning." The partners also invited university researchers to conduct research at the site (soil and plant tissue testing for possible contaminants, etc.). Using a workshop format, the researchers shared their results with the participating residents. The site was also open to university students to complete projects and conduct research. More than 650 students participated over a 4-year period.

Results/Outcomes

The OVGG is developing measures of evaluation of both qualitative and quantitative data. Quantitative measures focus on participation by the OVGG's youth group and other community members. OVGG uses the consistency of youth participation to assess level of commitment. OVGG uses attendance at public events to assess the success of community outreach efforts. For example, at least 80% of the youth will attend 75% of meetings, training, and public activities. OVGG assesses the development of the youth group's knowledge and skills using qualitative methods, such as debriefing sessions or pre- and post-participation surveys. The assessment examines the following areas:

1) **Impact of this project on core youths**
2) **Development of core youths' presentation skills**
3) **Development of core youths' leadership skills**
4) **Strength of core youths' commitment**
5) **Success of the overall outreach efforts**

A concrete outcome (though perhaps difficult to measure) of this project and partnership is the gradual building of the garden. A neglected brownfield in a neighborhood with a long history of exclusion, discrimination, and disinvestment was physically transformed from an empty lot into a flourishing garden, food forest, and research and learning hub. The OVGG has introduced trees, fresh fruits and vegetables, seating, space for socializing or quiet contemplation, learning workshops, and other events. It is difficult to quantify the impacts of this. So, we try to capture it qualitatively, via formal and informal feedback, conversations, and exchanges. Qualitative measures focus on changes in three areas:

- Increased levels of connection, trust, respect, and mutual exchange, both among community members and between community and campus partners
- Greater sense of ownership and belonging on the part of local community members toward the OVGG. They view the garden as a shared asset; a neighborhood hub for gathering; and a place of refuge, safety, nourishment, connection, learning, and joy.
- Increased access to healthy food and other resources, nature, social and educational connections, information, and opportunities, all contributing to improved physical and mental health

Challenges/Lessons Learned

The lessons learned are not necessarily new, but rather confirm that residents are willing and able to participate fully in solutions to issues that negatively affect their quality of life. With OVGG serving as a community garden and learning hub, residents can use the space to co-create and share knowledge that is effective and responsive to specific challenges of the local community. Recent events and workshops have provided insight on how to start hosting events that have a wider appeal for the community. The goal is not only to have a larger turnout, but also to respond more clearly to the interests and concerns of local residents. The community determines what the workshops are, and their input helps to set priorities. This particular project demonstrated that partners can effectively administer civically engaged research if they design it within a framework of mutual respect and benefit.

Implications for Advancing Health Equity

We know from the literature that access to nature, greenspace, and urban gardens promotes good health via multiple pathways. These include greater access to fresh fruits and vegetables, stress reduction, social engagement and cohesion, physical exercise, and cooling in an urban heat island (Twohig-Bennett & Jones, 2018). It is also clear that these positive health impacts are important in communities burdened by poverty, environmental racism, and other forms of structural violence (Bikomeye et al., 2021). Our observations and conversations with residents confirmed the power and potential of a space like the OVGG. The garden is a resource co-created with and for the local community to foster health, well-being, and social capital. OVGG is still growing, cultivating trust and connections. Building a shared sense of belonging and ownership takes time. The physical and social infrastructure is already in place. It fosters positive change at multiple levels, resulting in both direct and indirect effects on health and health equity.

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Example: The Truth Fairy Project for Environmental Health and Justice

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Background and Purpose

In 1922, Exide Batteries, a lead-acid battery recycling plant opened in Vernon, California, approximately six miles southeast of downtown Los Angeles. For decades, this operation crushed, washed, and processed up to 40,000 lead-acid vehicle batteries per day. The densely populated neighborhoods surrounding the plant are home to predominantly working class Latinx residents. In 2014, community-based organizations in the Southeast Los Angeles area requested that the University of Southern California Community Engagement Program on Health and the Environment (USC CEPHE) participate in community-led meetings. The community had concerns about a former battery smelter that extracted metals. This partnership fostered closer relationships between the university and community organizations. The partners came together around the goal of ensuring that regulatory agencies and the Exide Batteries company take action to protect public health. In 2016, in response to community concerns, the partnership fostered the launch of a community engagement research project to assess legacy lead exposure in children.

Methods

As concerns regarding the exposure to lead and other toxic metals continued to rise, community organizations and residents started to demand assessment of soil contamination for homes near the smelter. They also wanted a clean-up plan and information on how to protect families, especially children, from lead exposure. After the smelter closure, East Yard Communities for Environmental Justice (EYCEJ) requested support from USC CEPHE to assess:

1) **The extent of the contamination in residential neighborhoods**
2) **The levels of exposure in the population, particularly among children**
3) **The impact of this exposure on the health and well-being of the residents**
4) **The scope of a health-protective remediation plan**

The USC CEPHE and EYCEJ worked with Icahn School of Medicine at Mount Sinai, whose laboratory has developed a method to assess in utero and early life exposure to multiple toxic metals using baby teeth. Parents often save their children's teeth, which offers archives of samples to generate evidence regarding exposures in the community. Called the "Truth Fairy Project," this community-academic collaboration aimed to understand prenatal and early life exposure to toxic metals possibly released by the smelter.

Results/Outcomes

This partnership integrated community mobilization with empirical research, informing residents about toxic metal exposures and improving the community's capacity to respond to a public health crisis. The laboratory partner analyzed a total of 50 baby teeth from 43 Latinx children who had spent their whole lives in this community. The laboratory analyzed the teeth for pre- and post-natal lead and arsenic levels. The findings from the Truth Fairy Project study suggested that legacy soil contamination in this community near a smelter was associated with prenatal and early life exposure to lead. Both pre- and post-natal tooth lead levels were significantly and positively associated with soil lead levels.

Application of the Principles of Community Engagement

The partnership conducted research as a collaborative process. Community participants' demand for research results was not driven solely by wanting to learn clinically actionable information, but also by wanting to learn information about themselves that they would not otherwise obtain. The use of biomarkers, together with the process of conducting collaborative research, helped with engagement in the political process and supported regulatory and legal action to create policy change. In addition, the intentional effort to integrate concepts of environmental health literacy into the collection and analysis of baby teeth demonstrates how community-based science can move people from awareness to action on issues of environmental justice. The Truth Fairy Project integrated community organizing at the grassroots level as an intentional strategy to support both public health action and related research. The Truth Fairy Project and the ongoing collaboration among social justice organizations and academics increased awareness. The project also supported local community power to transform the debate on battery smelter facilities and legacy lead contamination across California.

Challenges/Lessons Learned

- Direct involvement of the community in both the planning and performing of research encourages participation, community buy-in, and successful translation of research into protections to improve public health.
- There are often unique concerns specific to environmental justice and migrant communities. These include multiple and complex environmental and social exposures, coupled with fear or mistrust of government.

Lead exposures in communities around Exide Batteries in Los Angeles County, California, remain widespread and do not occur in isolation. Communities remain vulnerable to lead exposure via drinking water, lead-based paint in older homes, and soil in neighborhoods at the fence line of industry (Figure 4.2). Thus, while population lead levels have trended downward, lead exposure remains an environmental justice challenge. Efforts are underway to prevent future exposures in the most contaminated homes, but removing lead does not undo the harm from earlier exposures. There remains a need for a community-driven resilience plan to address the impacts of toxic exposures on quality of life.

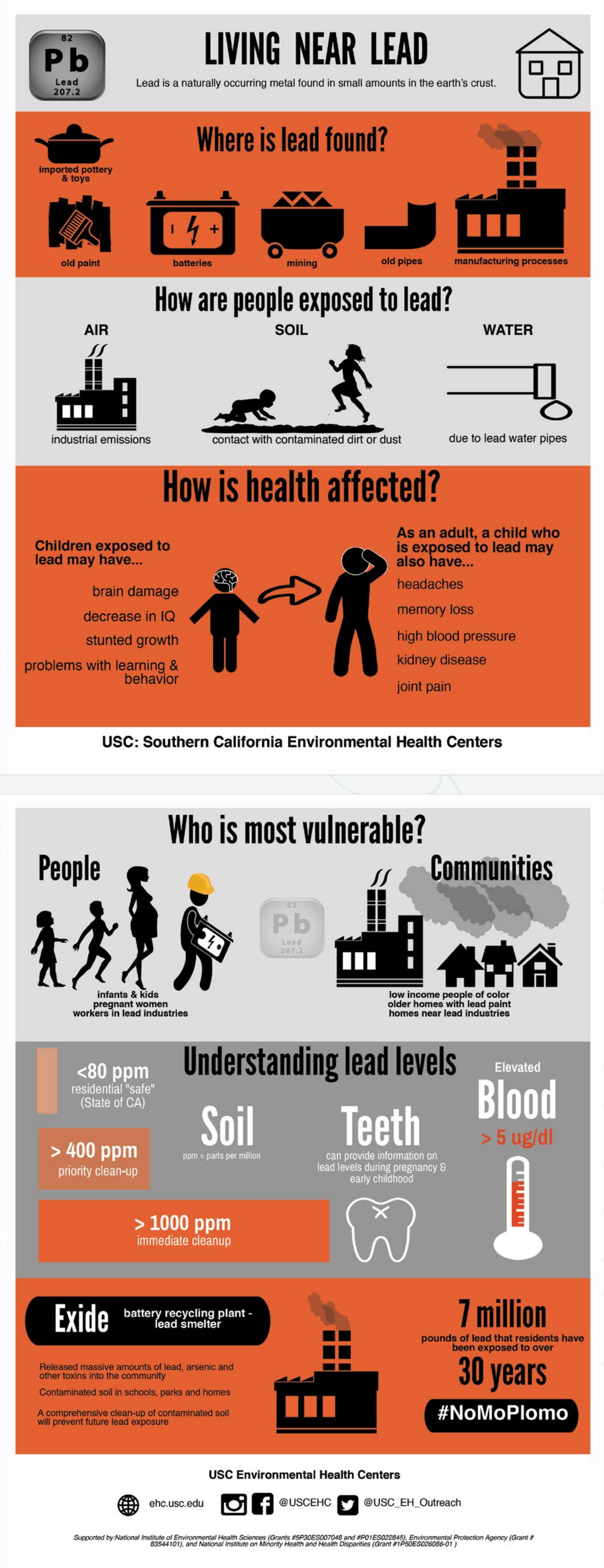
Implications for Advancing Health Equity

Community leaders, including key members of the Truth Fairy Project, in partnership with public officials and academics who met as part of a formal appointed advisory committee with governing bodies, resulted in:

- Extending the investigation zone to more than 10,000 properties up to 1.7 miles from the facility
- Securing funds to support remediation in the community
- Making all data regarding soil contamination publicly available and easily interpretable
- Establishing new regulations to reduce emissions from large battery smelters and other lead processing facilities to protect the health of children living near such facilities

The collaboration and focus on social justice and protecting public health shifted the debate in California on lead exposure and legacy lead contamination. It also led to implementing systemic change.

Figure 4.2 Neighborhoods at the Fenceline of Industry



Example: The Shaheed DuBois Exposome Roadshow and Community Grant Program

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Background and Purpose

The Clarence "Shaheed" DuBois Exposome Roadshow and Community Grant Program (The Program) supports a community to organize, plan, take, and sustain action around a community-identified environmental health concern, with the goal of improving community health. The Program focuses on the "exposome" defined as the composite of every exposure to which an individual is subjected from conception to death. This provides a holistic approach to understanding the environment's contribution to health and disease across the lifetime (Miller & Jones, 2014). The HERCULES Exposome Research Center at Emory University (HERCULES) stakeholder advisory board (SAB) guides HERCULES' community approach. The SAB includes residents, nonprofit organizations, academic partners, and local, state, and federal government agencies.

HERCULES and the SAB collaboratively developed The Program to:

- Increase community awareness of the exposome concept
- Incorporate the community's knowledge into the academic definition of the exposome
- Provide a structured mechanism to encourage community action
- Enhance community capacity to address local environmental health concerns

Methods

The Program begins with a 2-day Exposome Roadshow Workshop held in the community. The goal is for community members to come together to identify environmental health concerns in their community and begin to mobilize around a priority issue for action. Next, the community receives a small 3-month planning grant to organize around the identified priority issue and develop an action plan. The community implements the action plan using the Action Grant (for 11 months). The Program's final phase, the Sustainability Grant (11 months), allows the community to develop and carry out a plan to sustain their newly formed community group and efforts. Their plan includes identifying organizational capacity goals, a crucial component of program sustainability. HERCULES provides structured technical assistance during each phase of The Program. Technical assistance includes one-on-one and formal group trainings on topics such as:

1) **Leading action-planning discussions**
2) **Developing mission statements**
3) **Identifying roles and responsibilities**
4) **Planning and facilitating meetings**
5) **Assisting with organizational structure**
6) **Identifying collaboration opportunities that involve a student, a SAB member, or a HERCULES scientist**

Results/Outcomes

Six communities have participated or are participating in The Program and have identified and mobilized around a priority issue. All communities participated in our program evaluation, reporting their accomplishments and changes in community capacity. For example, one community group used the Action Grant to develop an action plan detailing the steps needed to address air and water quality related to industrial pollution in their community. Using their Action Grant, they promoted a citizen science odor reporting app to document industrial odors that resulted in more than 700 resident-authored odor reports. They also partnered with HERCULES scientists to measure specific air pollutants using community science. As part of their sustainability planning, they refined their goal to include training residents in community science and identifying different community members to take the lead in various roles to sustain the group.

The community's use of community science led to revisions to the city's industrial zoning codes. It also resulted in a meeting among the area's state representative, the mayor, city staff members, and the state's environmental protection division. Following this meeting, the mayor shared the documented community concerns with the company responsible for the odorous emissions. This has initiated dialogue between the company and residents, resulting in a proposed odor mitigation plan. Participating communities have also demonstrated improvements in various dimensions of community capacity, including participation, leadership, skills, networks, sense of community, and community power (Freudenberg et al., 2011). The impact is best described by this reflection on The Program from a community leader: "We change our communities one day at a time just by identifying…and asking… 'do you have environmental hazards?'… This is why we're at the table today."

Challenges/Lessons Learned

The community groups that participate in The Program are typically small volunteer groups. The size and volunteer nature of the groups can present challenges regarding time commitment, project scope, and needed expertise or skill sets. As such, we encourage them to narrow their project scope and identify specific roles and tasks for group members. These small community groups can also face industry opposition, government bureaucracies, and complex technical documentation. The Program alleviates some of these barriers by providing a direct connection to experts within those bureaucracies, supporting community advocacy efforts, and enhancing community power.

Implications for Advancing Health Equity

The Program has the potential to advance health equity by prioritizing environmental justice in communities that face long-standing disinvestment and multiple compounding issues. Once in The Program, we support communities through structured financial and technical assistance to rally around one priority issue. In our experience, strengthening capacity around one issue mobilizes the community to act on additional issues. As discussed by Freudenberg et al. (2011), strengthening community capacity in this way plays a critical role in reducing environmental health inequities.

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Appendix 4: Accessible Descriptions for Complex Graphics

Figure 4.1—Conceptual Model for Evaluating Community-Academic Partnerships

Figure 4.1 presents the Conceptual Model for Evaluating Community-Academic Partnerships cycle and connections.

The top of the cycle is Organizational and Community Characteristics, including

- Previous collaboration
- Community response to the concern or issue
- Geographic and cultural diversity
- Social and economic conditions/social determinants
- Challenges (e.g., institutional policies, competing priorities of organization and community, regulations/laws)

The Organizational and Community Characteristics can link directly to 5 other parts of the cycle, which also are connected to each other. The first link is **Partnership Programs and Interventions**, which is connected to the other 4 other areas of connection in the cycle. These are:

- **Structural Characteristics,** such as membership, complexity, and formalization.
- **Group Dynamics and Characteristics of Effective and Equitable Partnerships**, including
    - Multi-directional, open communication
    - Well-organized meetings with collaboratively developed agendas and facilitation
    - Development of mutual trust
    - Cooperative development of priorities and shared vision
    - Participatory decision-making processes
    - Agreed upon problem-solving processes
    - Constructive conflict resolution
    - Leadership and power structures (shared leadership, power, influence and resources)
    - Collaborative evaluation of both task/goal and process objectives
- **Intermediate Measures of Partnership Effectiveness and Equity**
    - Effectiveness of the group in achieving its goals
    - Personal, organizational and community benefits of participation
    - Focus on equity within partnership processes
    - Focus on advancing health equity
    - Capacity and ability of communities and partners to engage in future partnerships and decision making
    - Extent of member involvement
    - Joint communication and dissemination of activities, and lessons learned
    - Shared ownership and cohesiveness/commitment to collaborative efforts
    - Shift in power benefiting communities that are experiencing inequities
    - Creating and strengthening social ties
    - Partnership synergy
- **Long-Term Outcome Measures of Partnership Effectiveness**
    - Achievement of program and policy objectives (e.g., collaborative problem solving, health indicators)
    - Reduced health inequities and inequities in the social and environmental determinants of health
    - Institutionalization of programs and/or partnerships
    - Improved capacity in addressing shared priorities

◀ *Return to Figure 4.1*

Figure 4.2—Neighborhoods at the Fenceline of Industry

Figure 4.2 is an infographic titled *Living Near Lead*. It has the chemical symbol for lead and a drawing of a house. It reads, *lead is a naturally occurring metal found in small amounts it the earth's crust*.

The infographic is divided into 5 topics.

Topic 1: Where is lead found? It has illustrations that are titled

- Imported pottery and toys
- Old paint
- Batteries
- Mining
- Old pipes
- Manufacturing processes

Topic 2: How are people exposed to lead? It includes drawing that are titles:

- Air, industrial emissions
- Soil, contact with contaminated dirt or dust
- Water, due to lead water pipes.

Topic 3: How is health effected? It shows stick figures of a child and adult. It states:

- Children exposed to lead may have
  - Brain damage
  - Decrease in IQ
  - Stunted growth
  - Problems with learning and behavior
- As an adult [a child sic] who is exposed to lead may also have
  - Headaches
  - Memory loss
  - High blood pressure
  - Kidney disease
  - Joint pain

Topic 4: Who is most vulnerable? It uses drawings of people, a lead symbol, a factory, and homes. It reads:

- People
- Infants and kids, pregnant women, workers in lead industries
- Communities
- Low-income people of color, older homes with lead paint, homes near lead industries.

Topic 5: Understanding lead levels. The images in this topic include a stripe for soil, a tooth, a vial, and an industry. The topic states:

Less than 80 ppm in soil (part per million) is residential safe in California and greater than 400 ppm is priority clean-up. Teeth can provide information on lead levels during pregnancy and early childhood. Elevated blood levels in blood are greater than 5 micrograms of lead per deciliter of blood.

The factory in this topic is Exide battery recycling plant and lead smelter. The topic reads that Exide:

- Released massive amounts of lead, arsenic and other toxins into the community
- Contaminated soil in schools, parks, and homes
- A comprehensive clean-up of contaminated soil will prevent future lead exposure
- 7 million pounds of lead that residents have been exposed to over 30 years, #NoMoPlomo.

The citation line reads: *USC Environmental Health Centers*.

◀ Return to Figure 4.2

CHAPTER 5: OPPORTUNITIES FOR FACILITATING COMMUNITY-ENGAGED RESEARCH

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This chapter discusses key challenges of community-engaged research, practices with potential to address these challenges, and opportunities based on practices applied across institutions. This chapter details resources for community-academic research teams to build a trusted foundation for community-partnered research. Vignettes featuring real-life examples illustrate the chapter discussion. The vignettes highlight four cornerstone topics:

1) **Building Equitable Partnerships**
2) **Maintaining Partnerships over Time**
3) **Creating Infrastructure to Support Community-Partnered Research**
4) **Embracing Digital Technology**

The vignettes provide snapshots of how community-academic partnerships can create solutions to challenges encountered throughout the research process. Each vignette is grounded in the principles of community engagement. The vignettes demonstrate how important it is to:

- Understand communities
- Establish trusting, respectful, fair, and committed relationships
- Work with the community to identify the best ways to translate knowledge into improved health

A planning meeting. *Lloyd DeGrane, 2019*.

Snapshot: Building Equitable Partnerships: Co-Defining the Research Goals

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Editors' Note: *This project references tobacco use among American Indian youth, who in the 1990s were at high risk for smoking. Currently, e-cigarettes (vapor) are the most commonly used tobacco product among youth, including those who are American Indian (Centers for Disease Control and Prevention, 2023). While this vignette highlights smoking of traditional cigarettes, the methods used were effective and could be modeled in current campaigns that address e-cigarette use (vaping). For example, in 2022, the United States Food and Drug Administration (FDA) launched the Next Legends Youth E-cigarette Prevention Campaign. This campaign focused on American Indian and Alaska Native youth ages 12–17, as they are more frequent users of e-cigarettes. The FDA included American Indian and Alaskan Native youth in developing effective messaging related to tobacco use. The FDA also partnered with a Native-owned advertising agency to develop messaging (United States Food and Drug Administration, 2022). In addition, the smoking cessation program highlighted in this vignette, Not On Tobacco (N-O-T) is still used today. It is promoted by the American Lung Association to address tobacco use through smoking and vaping (American Lung Association, 2024).*

Challenge

At the time of our work, American Indian youth were one of the demographic groups at highest risk for smoking (Johnston et al., 2004; Rock et al., 2007). Yet there was little research about effective interventions for American Indian teens to prevent or quit smoking. American Indians have a long history of negative experiences with research. In their review of 55 peer-reviewed articles and grey literature (e.g., government publications), Brockie et al. (2022) highlighted the need for cultural safety in research, which considers social, political, economic, and historical contexts that shape health outcomes. The authors draw attention to a lack of inclusion of cultural knowledge and other factors, which has led to distrust in research among Native American populations. Daley et al. (2011) discussed low success rates for smoking cessation among American Indians. They attribute the low success rates to a lack of culturally appropriate cessation programs that acknowledge the traditional use of tobacco. In addition, tobacco historically had economic, spiritual, and cultural significance in American Indian culture (Horn et al., 2008). In light of these factors, American Indians may have had minimal involvement in research on tobacco addiction and cessation in their communities.

In the late 1990s, we were part of the West Virginia Prevention Research Center (PRC). Through the PRC, we conducted research with several community partners on teen smoking cessation in North Carolina, largely among white teens. One result of this collaboration was that members of the North Carolina American Indian community approached us about addressing smoking among American Indian teens, focusing on state-recognized tribes.

This request for partnership provided both a challenge and an opportunity. We had to address the harmful health effects of youth smoking addiction in high-risk communities, of which some received economic benefits through tobacco as a cash crop (Horn et al., 2008). As we began to meet with the community, we discussed the spiritual and economic roles of tobacco in American Indian culture. We, the researchers, saw tobacco as the problem, but many community members did not share that view. This was a significant issue to resolve before the project could move forward. A major breakthrough occurred during one meeting, when community partners reached a declarative insight that tobacco addiction, not tobacco, was the appropriate framing for our collaboration. From that day forward, the group agreed to develop a program on smoking cessation for teens that specifically addressed tobacco addiction from a cultural perspective.

When working with communities that have historically been (and may still be) underserved and exploited, such as American Indians, CBPR approaches can be particularly effective. For this reason, CBPR approaches served as the framework for a partnership that included the University of West Virginia PRC, the North Carolina Commission of Indian Affairs, the eight state-recognized tribes, and the University of North Carolina's PRC.

Practices with Potential for Success

Our CBPR-driven process began with forming a multi-tribe community partnership board of tribal leaders, parents, teachers, school personnel, and clergy. In partnership with the community board, we developed a document of shared values to guide the research process. We obtained community input regarding the nature of the program from focus groups, interviews, surveys, and informal discussions, including testimonials and numerous venues for historical storytelling.

Using CBPR approaches, the community decided to use as the starting point the evidence-based Not On Tobacco (N-O-T) program developed by the University of West Virginia PRC. The community wanted to adapt the N-O-T for American Indian teens. The American Lung Association promotes the N-O-T program, which is still in use today (2024). N-O-T broadly addresses teen smoking and vaping cessation (American Lung Association, 2024). American Indian smokers and nonsmokers, N-O-T facilitators from North Carolina, and the community board all provided input into the original N-O-T program. In addition, teen smokers provided session-by-session feedback on the original N-O-T program. The community partners and teens made numerous recommendations for tailoring and modifying N-O-T, leading to a new N-O-T curriculum for American Indians. The American Indian N-O-T adaptation provided 10 tailored sessions that included:

- Information about tobacco use rates, health effects, and historical context of tobacco among American Indian populations
- Enhanced focus on the impact of teen smoking on family and community
- Youth leadership and advocacy (Horn, Dino, et al., 2005; Horn et al., 2008; Horn, McGloin, et al., 2005)

Carolina. Over a multi-year period, from 1998–2003, we conducted N-O-T school programs. Participating states included West Virginia, Florida, North Carolina, New Jersey, and Wisconsin.

We conducted the North Carolina American Indian N-O-T from 2003 through 2004. This program served as a springboard for localized planning and action for tobacco control and prevention across North Carolina tribes (Horn, et al., 2005). Various tribes across the United States made ongoing requests for program information. Our initial partnership was supported by goodwill and good faith. Our partnership with American Indians led to additional collaborations in North Carolina. Collaborations included a three-year CBPR project to further test the American Indian N-O-T program and to alter the political and cultural norms related to tobacco across North Carolina tribes. Critically, grant resources were divided among the West Virginia PRC, the North Carolina PRC, and the North Carolina Commission on Indian Affairs. Each organization had monetary control over its resources.

Possibilities for Positive Community Engagement Practices

Our collective experience enabled us to identify the following positive practices for community engagement (Horn, McGloin, et al., 2005):

- Act on the basis of value-driven, community-engaged principles, assuring recognition of a community-driven need. This allowed us to respond to community needs and perspectives.
- Build on the strengths and assets of the community of interest through listening, dialoguing, doing homework, and demonstrating cultural humility. Recognize unique community strengths and assets. In our practice, these strengths included family ties, natural networks, and the important work of promoting the health and well-being of youth.
- Nurture partnerships in all project phases and recognize the iterative nature of the partnership. Encourage and sustain trust through regular open communication, delivering on promises, ongoing commitment, and willingness to discuss challenging issues related to discrimination, oppression, and power imbalances.

- Understand the culture and experiences of community partners. This allowed us to appreciate the realities in which our partners operated.
- Produce mutually beneficial tools and products, resources, and services that increase community capacity, enhance community empowerment, and add to the research base. Ensure that tools and products are culturally relevant and may include input from the community.
- Develop strategies for translating research findings to inform health policy and practice.
- Build capacity through co-learning and empowerment. One way to support resource sharing is for institutions to offer grants for partnership development, translation, and dissemination of research findings. These activities are not often covered by traditional funding sources. Such funding will allow for the CBPR process to unfold.
- Share all findings and knowledge with all partners. Working with all partners to identify and implement research translation and dissemination strategies appropriate to various partners enhances research impact and further sustains trust.

Maintaining Partnerships over Time

Snapshot: The Patient Voices Network: The Role of Patient Ambassadors in Improving Health

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Background and Purpose

The Patient Voices Network (PVN) formed in 2010 in collaboration with the University of Buffalo. The PVN developed and implemented a practice-based intervention to increase cancer screening among patients with complex medical and socioeconomic situations. The role of PVN was to advise researchers and clinicians on prioritizing cancer screenings and to develop appropriate actions. At study completion, patients expressed interest in continuing efforts to improve health equity in their communities through research and service. The PVN's vision is a community of educated and involved patients who make decisions about their own healthcare by working hand in hand with clinicians. Currently, there are 23 active members of the PVN; 87% are African American, 9% are white, 9% are Hispanic, and 4% are multiracial. Most (96%) live in high-poverty ZIP codes in the city of Buffalo, New York. A PVN steering committee meets twice a month to discuss the PVN's research agenda, develop policies for partnering with researchers, and provide insight into the needs and concerns of the PVN's respective communities.

In 2013, PVN recognized the need to increase mammography screening in their communities. The University of Buffalo and PVN linked mobile mammography with under-resourced primary care medical groups. But doctors expressed concern over the potential increase of patient volume and staff burden on days that the mobile unit was on site. In response, the University of Buffalo and the PVN used Patient Ambassadors to take the burden off the clinics.

Methods

The Patient Ambassadors model has been used in a variety of projects. The model encourages patients to advocate for themselves through open communication with their providers. Patient Ambassadors participate in ongoing training related to professionalism, leadership, content areas, and project-specific protocols. Patient Ambassadors can offer patients and clinics a wide variety of support. Broad responsibilities of the Patient Ambassadors include:

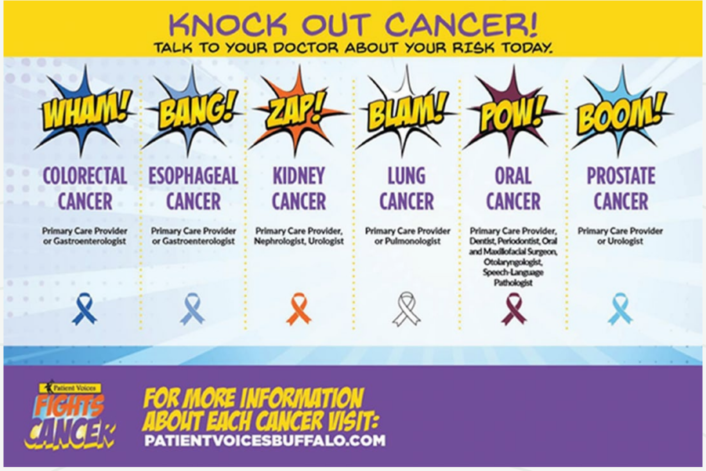
- Scheduling (mobile mammography or in clinics)
- Hosting mammography days (in partnership with mobile mammography)
- Conducting outreach
- Following up with patients
- Making reminder calls
- Encouraging colorectal cancer screening
- Describing the process for participation in research (not specific research trials but the process of research participation)
- Training providers
- Creating educational materials

Patient Ambassadors can adapt their workflow to meet the needs of both the clinics and the patients with whom they are interacting. Because most of their work is done by phone, they worked during the COVID-19 pandemic, despite changes in clinic workflow and other aspects of the environment.

Results/Outcomes

Eight PVN members are active Patient Ambassadors, serving a variety of projects. A Patient Ambassadors team developed educational infographics on six cancers (kidney, lung, colorectal, oral, esophageal, and prostate) with high incidence rates in their communities (see Figure 5.1). These infographics have a wide distribution through the various clinics that partner with the Patient Ambassadors.

Figure 5.1 Knock Out Cancer Educational Infographic



In the effort to increase mammography screening, nine practices providing care to predominantly low-income minority women participated in the program. In eight years, Patient Ambassadors have contributed to the completion of more than 5,000 screening mammograms. The clinics favorably view the role of the Patient Ambassadors. The Patient Ambassadors have developed relationships with two mobile mammography units and are helping to schedule women at freestanding screening sites.

Two practices are working with Patient Ambassadors to increase colorectal cancer screening. The PVN developed relationships with two primary care practices, gastroenterology screening practices, and colorectal surgeons. On a systems level, Patient Ambassadors have succeeded in identifying systemic barriers that prevent screening. On a practice level, their efforts have led to changes that include better referrals and processes for screening tests.

Challenges/Lessons Learned

Funding is a means to an end, but aligning mission and commitment is more important. We have learned to be diverse in where we obtain funding. We are not shy about asking for funding and to plan and prepare for times when we work without funding. PVN and the University of Buffalo agreed that they would continue their partnership after a gap in funding. During that time, they selected projects that were not costly but had impact, such as improving signage within a practice.

To move forward, the leadership must balance the needs of the community and interests of the PVN with the number of collaborative projects. The PVN Steering Committee is instrumental in making these decisions. We are also looking for other partners interested in various topics so we can participate in, rather than lead, new project ideas. Membership in PVN grows when we have projects that require active participation.

We had to adjust and adapt our implementation strategies because of the COVID-19 pandemic. The pandemic initially prevented us from reaching as many people as we had in the past. Our adaptations have opened opportunities for us that could broaden our reach moving forward.

Application of the Principles of Community Engagement

- We started our partnership with clear goals and expectations. We develop these goals and expectations together. The PVN are experts about the history and culture of their community.
- Members of PVN are open about the challenges they face in health care. They have indicated how the community may negatively perceive well-meaning practices or policies.
- The PVN has the power to say no to projects that do not suit their mission. They have policies that outline project selection. As the PVN brings ideas to the table, their involvement continues in all stages of project development.
- The PVN has implemented interventions and presented the work in the community and at national research conferences.
- The PVN members bring their individual strengths and expertise and assets of the community to our team. This results in increased screening and sustainable change in the community.
- Through our broader practice partnerships, we have improved systems of care that the practices sustain. Members of PVN and the larger community benefit from health education and share that knowledge in their community.
- We have supported our partnership and have demonstrated trustworthiness by offering support such as workspace, access to computers and phones, and internet availability.
- The key to the longevity of our partnership of 12 years has been our commitment to action and change.

Implications for Advancing Health Equity

Patient Ambassadors, a peer model of support, have become a proven resource in primary care. They have a solid history in increasing cancer screening in underserved communities, as well as in helping patients manage their chronic diseases. They ground their work in addressing SDOH and increasing communication between patients and providers.

A patient advocate providing information to a patient. *Public Health Image Library, 2011.*

Snapshot: Maintaining and Scaling an Established Community-Engaged Research Coalition Board

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[d] Georgia Primary Care Association, Decatur, Georgia

Challenge

A research governance body that ensures active involvement of members in community-engaged research requires that community advisory boards embody community engagement principles. The boards should attend to evolving member values and satisfaction. The boards also should be sensitive to the opportunity to be inclusive through increasing the capacities of non-members. These aspects broaden the network of community-engaged leaders. Community coalition boards need resources and other support to build and maintain their capacity, power, and infrastructure. Such support enables them to govern rather than advise on research designed to advance health equity.

The Morehouse School of Medicine Prevention Research Center (MSM PRC) incorporates the applied definition of community-based participatory research. In this definition, the MSM PRC conducts research with, not on, communities in a partnership relationship. Central to the MSM PRC is the Community Coalition Board (CCB), composed primarily of community members. The CCB welcomes an iterative process of disagreement, dialogue, and compromise. This ultimately results in identifying what academicians offer communities for research initiatives that the community deems valuable and what academicians need from neighborhood board members. For more than 20 years, the CCB has engaged in community research. The communities have witnessed and sustained change. The CCB has expanded to govern community-engaged research that occurs in the Georgia Clinical and Translational Science Alliance, as well as in many other grants and partnerships.

Promising Practice

Opportunities for reliable funding, capacity-building, and collaborative dissemination have been essential for the CCB and the broader community. Community-based organizations (CBOs) submit proposals for competitive grants as principal investigators. They partner with research collaborators, who provide financial resources, training, and technical assistance in community-engaged research and grant writing, thereby strengthening their organizations.

In 2012, new Community-Engaged Research Committees expanded the group of researchers that could partner with community experts. Composed of a small group (three to five) of board members and other identified leaders, they offered expertise and networks that strengthened specific research studies or relationships with priority populations. This structure encouraged understanding and exemplified community-teamed science. CBOs also served as co-investigators or co-principal investigators on federal government grants. This transformed team science models and broadened research networks to include community experts as equal partners. Community-members co-authored peer-reviewed publications and community and policy briefs, which demonstrated a commitment to dissemination with and not solely about community-engaged research partners. A web-based searchable database was established in 2019 to facilitate community-engaged research partnerships in Georgia. The data base provided over 500 community and research profiles of those interested in collaboration, further expanding the network of opportunity and expertise.

In 2011, the CCB developed and administered an annual to provide input through an iterative process. Elements included:

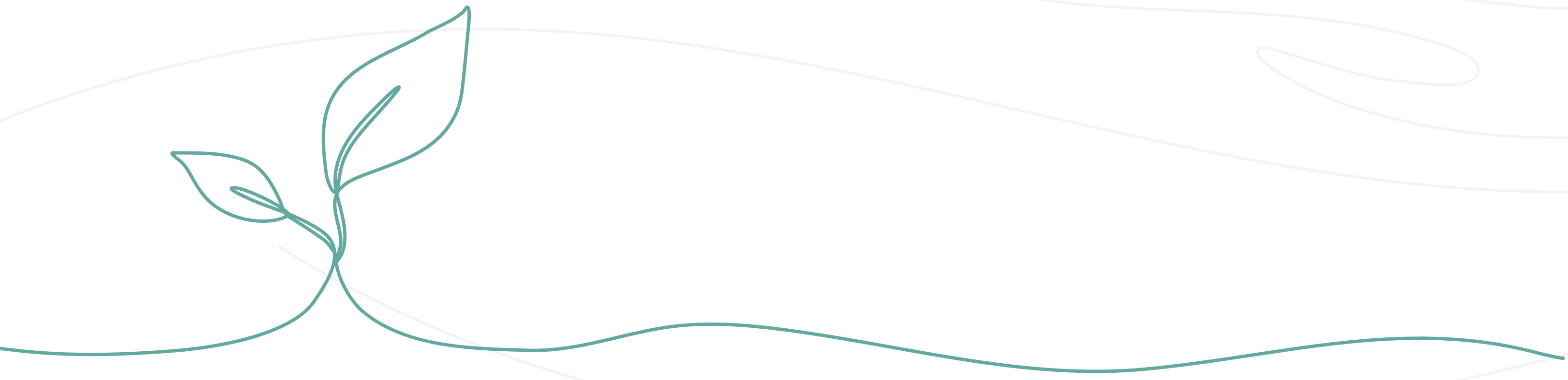
- Self-reflection
- Assessment of relationship dynamics
- Assessment of value of knowledge, time, and talent

CCB reviewed the assessment results during a yearly retreat with candid discussion on improvement, regression, and sustained success (Braithwaite et al., 2020; Henry Akintobi et al., 2011).

Possibilities for Positive Community Engagement Practices

The CCB is at the forefront of ensuring that work closely aligns with research practices and outcomes that benefit the community and board members alike. The CCB identified several beneficial practices:

- As much as possible, board members in the majority and in leadership seats should represent the community and its priorities. Agency staff members (e.g., health department staff members, school principals, industry) and researcher members may be essential, but are often not representative of the lived experience needed to ensure community-engagement credibility.
- Board members that represent historical positions of greater power (academic, industry, or clinical) must regularly identify capacity-building and funding opportunities for and prioritized by community members. They must nurture community-led capacity-building to develop community trustworthiness in research.
- Sustained, active community research board engagement requires assessing, prioritizing, and operationalizing board values. When the board acknowledges these values, all members are more invested and accountable.
- Boards are more respected when they provide opportunities for others to learn and lead by way of a community-engaged research network (capacity-building, research leadership, and financial resources). This establishes a culture of equity, inclusion, and expanded leadership to advance health equity.
- Researcher trustworthiness may be a challenge, particularly during public health crises. The challenge may arise due to health, social, and political inequities for those disproportionately affected and previously less represented in research. Community coalition boards with the power and resources to affect research policy (rather than solely advise) sustain trust and power in the role of community research governance toward improved and sustained community participation in research.



Creating Infrastructure to Support Community-Partnered Research

Snapshot: Training Programs for Nontraditional Researchers

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Challenges

Many community research partners engage in recruitment, informed consent, data collection, and other research activities. These activities require training in human research protections and research ethics. However, most training program content is geared to for learners who are already familiar with research methods and terms. These programs do not address the unique context of community-engaged research. As such, community-engaged research teams may not have a favorable opinion of these programs and materials. This creates a barrier to both timely study initiation and to authentic and fair engagement.

Promising Practice

Around 2009, individuals affiliated with clinical and translational science award (CTSA) programs at University of Illinois Chicago (UIC), Northwestern University, and University of Chicago formed the Chicago Consortium for Community Engagement (C3). The aim of C3 was to foster collaboration among Chicago CTSAs.

Community-engaged research teams were looking for a human research protections training program for community partners. In addition, they wanted the training to meet the requirements for acceptance by all research institutions in Chicago. C3 hosted focus groups with members of community-academic research partnerships, which led to a new training, CIRTification: Training in Human Research Protections for Community-Engaged Research Partners (Anderson, 2015). Developed and supported by the UIC Center for Clinical and Translational Science (CCTS), CIRTification is available in online and in-person formats in both English and Spanish and free to everyone. The trainings use interactive learning strategies to:

- Introduce community partners to the rules and regulations for conducting human research
- Emphasize the importance of keeping safe research participants and their data
- Help participants translate their unique knowledge and skills to research collaborations

The online version of CIRTification first covers research basics, including terms, people, and methods. The program further reviews the history of research abuses that have informed current ethical principles, rules, and regulations. The training then covers standards and best practices for recruitment and informed consent, collecting and protecting data, and handling challenges that may arise during participant interactions. CIRTification reviews the role of Institutional Review Boards (IRB) in protecting the rights and safety of research participants. CIRTification includes a dictionary of research terms and a toolbox with resources related to human research protections.

Community partners, research ethics experts, and human research protection program administrators reviewed proposed CIRTification materials. Based on this review, CCTS created a facilitator manual and participant workbook with presentation materials and activities. CCTS then launched CIRTification Online, a virtual interactive training program with audio and video as well as text, using plain language and user-friendly materials. In 2021, CCTS created a Spanish version of CIRTification Online. In 2023, CCTS partnered with the Miami Clinical and Tranlsational Science Institute to create a Haitian Creole version.

As of publication, over 5600 individuals have completed CIRTification Online, and almost research 60 institutions promote its use. Learn more at https://ccts.uic.edu/resources/cirtification/.

Possibilities for Positive Community Engagement Practices

Many community-academic research partnerships could benefit from a human research protections training program tailored for community partners. The CIRTification program fills the gap. As more academic institutions see the benefits of partnering with community advocates and collaborators in research, demand has grown (University of Illinois Chicago, 2023). CCTS encourages researchers to determine whether their institution accepts CIRTification or other human research protections training that appeals to community research partners.

Snapshot: Including Community Voices in Study Design

Tiffany Israel,[c] Aima Ahonkhai,[b] Leah Dunkel,[a] Devan Ray,[c] Yolanda Vaughn,[d] Stephania T. Miller-Hughes,[e] on behalf of the Meharry-Vanderbilt Community Engaged Research Core

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[c] Vanderbilt University Medical Center, Institute for Clinical and Translational Research, Nashville, Tennessee

[d] Community Advisory Board member, Vanderbilt Institute for Clinical and Translational Research; Community Development Specialist, Nashville, Tennessee

[e] Meharry Medical College, Nashville, Tennessee

Challenge

Most biomedical researchers do not have training or experience in engaging community members. At the same time, many academic institutions lack adequate infrastructure to support community engagement in a meaningful way. To address this unmet research need, in 2007 investigators at Vanderbilt University Medical Center (VUMC) and Meharry Medical College (MMC) launched the Meharry-Vanderbilt Community Engaged Research Core (CERC). CERC is part of Vanderbilt's larger Clinical and Translational Research Center (Vanderbilt Institute for Clinical and Translational Research, VICTR).

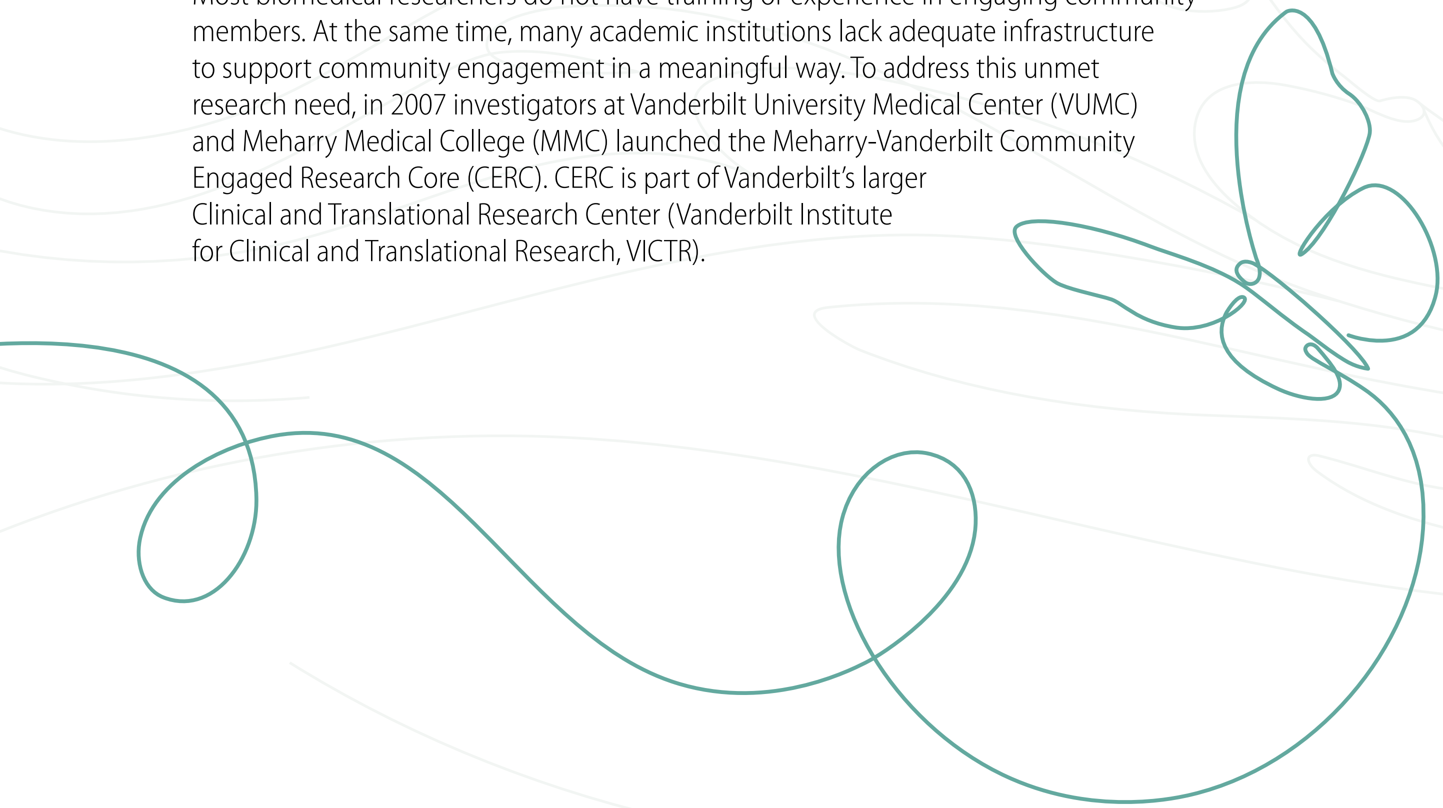
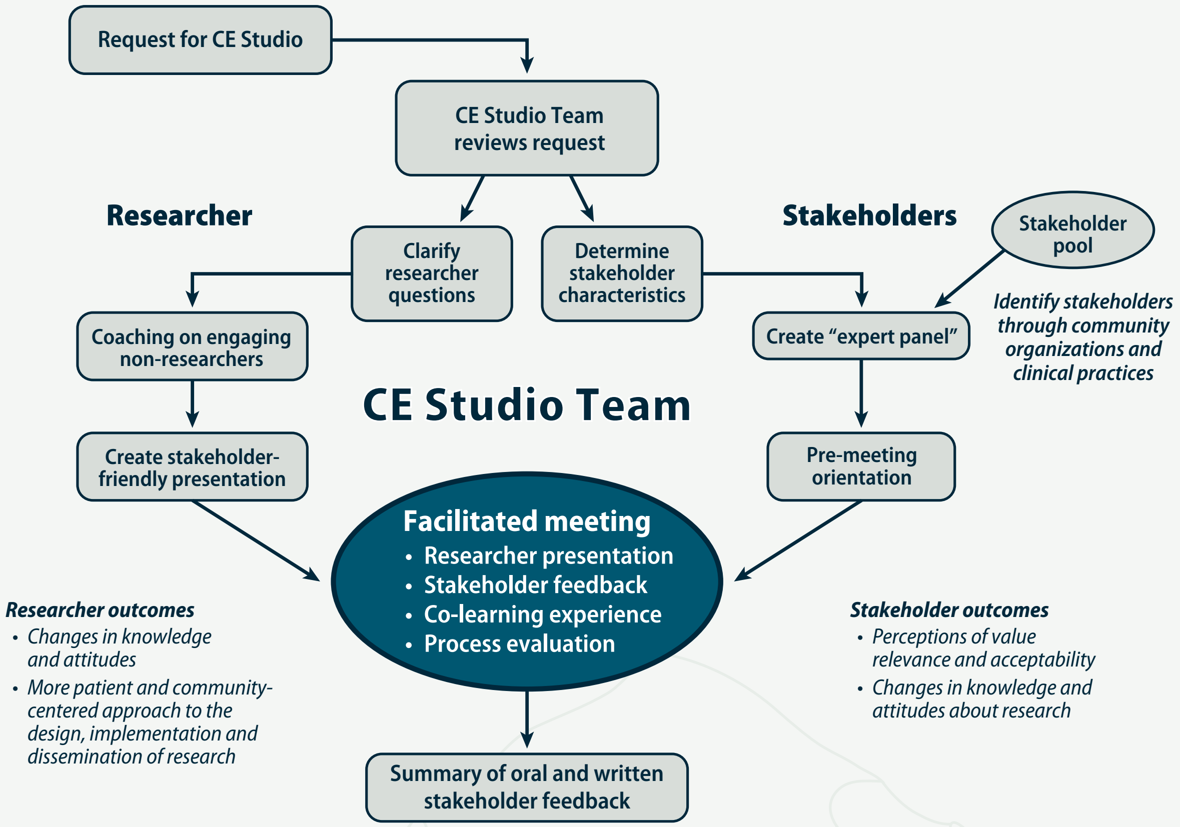


Figure 5.2 The Community Engagement Studio Structure, from Joosten et al. (2015)



https://journals.lww.com/academicmedicine/fulltext/2015/12000/community_engagement_studios__a_structured.26.aspx

Promising Practices

In 2009, the Meharry-Vanderbilt CERC expanded the VICTR's Clinical and Translational Research Studio model for strengthening research proposals with input from academic experts (Byrne et al., 2012). The CERC developed the Community Engagement Studio (CE Studio) as a structured approach to engage community and patients/partners in research (Figure 5.2; Joosten et al., 2015). Different from most methods of community engagement, the CE Studio has a dedicated team with experience in patient and community engagement to recruit partners. The team includes:

- A Navigator to prepare and coach the investigator
- A Facilitator to guide the interaction between study team and community partners
- A Scribe to take notes to capture feedback
- A Community-Engaged Research Specialist.

Example of CE Studio

Table 5.1 provides an example of a CE Studio project. The project was a 3-year randomized, multicenter trial of patients with acute heart failure (AHF). The project compared discharge directly from the emergency department (ED) or after a brief period of ED-based observation with a personalized discharge plan (Collins et al., 2017).

Table 5.1 Attributes of an Example of a Community Engagement Studio Project

FOCUS	TO ENHANCE CARDIAC CARE AND REDUCE REHOSPITALIZATION
Study Challenge	Identify patient priorities to include in customized discharge plans to increase likelihood of patient use.
Expert Characteristics	Patients (or their caregivers) who had come through the ED with heart failure.
Questions for Experts	• What challenges do you face living with AHF? • What could make this intervention more successful? • What challenges do you see for this intervention? • How would you define success? • What are your priorities in managing your AHF?
Recommendations	• Address barriers related to lack of finances and lost wages. • Improve the intervention by adding more tools and support for the patients and caregivers (mental health, patient education, creation of easy-to-use treatment plan). • Increase education and training of primary care staff members to support patients upon discharge.
Resulting Changes to Research Project	Added trial secondary end points to include: Out-of-pocket costs; lost wages owing to clinic visit; time spent in clinic visits. Home visit in intervention arm.

Possibilities for Positive Community Engagement Practices

Over 12 years of experience and input solicited from CE Studio project participants informed the CE Studio's prescribed structure and process. Researchers, community experts, community facilitators, and faculty and staff members provided input. Findings included:

- As a result of this innovative, consultative model, investigators have better understanding of contextual factors that directly affect their study design, implementation, and dissemination of findings. Both researchers and community experts agree that this model improves the quality of research (Joosten et al., 2018).
- The CE Studio can increase the relevance or patient-centeredness of a research project, respond to funder requirements for community input, or address challenges in an active project, such as participant recruitment or implementation (Johnson et al., 2015).
- The model is relatively easy to reproduce. Academic and other institutions should consider using the model to expand the capacity to conduct community-engaged research.

Embracing Digital Technology

Snapshot: Building Trust through Online Outreach

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Challenge

Communities of color have long experienced racism and oppression, which has resulted in mistrust toward health care delivery systems, medical research, and government agencies. Recently, social media has further promoted mistrust by spreading misinformation.

Promising Practice

Founded in 2008, the Southern California Clinical and Translational Science Institute and its Community Engagement core have worked to build trusting relationships with the community. We do so by first listening to and learning from the community, then partnering with the community to implement academic-community partnered public health strategies to address the community's most pressing health concerns. Our community engagement team includes promotores de salud (Spanish for "health promoters"). Our team works to bridge the gap between the community and biomedical researchers, create opportunities for bidirectional discussions, and promote community-partnered research. We approach engaging, educating, and empowering the community using four strategies:

1) **Education**
2) **Multimedia communication**
3) **Community-partnered research**
4) **Dissemination**

We conduct listening sessions with members of the community. We include trusted leaders, members of the faith community, and residents, to learn about the most pressing health-related concerns and needs, and then respond with educational offerings (e.g., workshops, trainings, townhalls) to address these needs. This includes bringing care providers and researchers with expertise in the requested areas to address and respond to community members' concerns and needs. Building authentic and trusting relationships with the community requires that academic institutions value community experts and compensate them for their time and contributions.

The community engagement team works with our partners to develop and deliver health-related information in engaging formats to oppose misinformation. We particularly focus on misinformation intended for underserved, underrepresented populations. Narrative storytelling has been a key strategy to both deliver evidence-based information and expose misinformation. Hollywood, Health, and Society is a collaboration between the community engagement team and the Norman Lear Center at USC's Annenberg School for Communication and Journalism. Together, we contributed to storylines in popular TV about clinical research, disease prevention, and health myths. The community engagement team has also partnered with Life Noggin to produce YouTube videos about clinical trials research, vaccines, mental health, isolation, drug overdose, and more.

In addition, we incorporated storytelling into "VaccinateLA," a community-partnered COVID-19 vaccination campaign. The multimedia campaign included educational workshops, townhall events, vaccination navigation, vaccination pop-up clinics, and digital media. It reached more than one million residents in Los Angeles communities with the lowest vaccination rates between April and September 2021. The campaign included:

- A series of 1-minute public service announcement videos
- Radio ads
- #ShareYourWhy videos
- Two short films written and produced by local student filmmakers

The campaign tackled misinformation, rumors, medical racism, and sources of vaccine indecision through relatable and powerful stories. The White House Coronavirus Task Force praised both short films for being an effective, culturally appropriate way to engage and encourage diverse communities to get the COVID-19 vaccine. We also developed a fotonovela, called "Infectious Rumors!" This was distributed to more than 50,000 community members.

To increase pediatric research participation, the community engagement team partnered with USC's Institute for Creative Technologies to develop Zippy, a fun and interactive virtual research navigator. Zippy provides information while addressing misinformation about clinical trial research and study participation. Zippy responds to questions using voice recognition and short animated films. People can access Zippy on a tablet, in both English and Spanish (Southern California Clinical and Translational Science Institute, n.d.).

In addition, community outreach and education activities include community events. We provide guest lectures, presence at health fairs, education on research, and healing circles where community members can express feelings of mistrust, oppression, and racism.

Possibilities for Positive Community Engagement Practices

Trust is key to engaging underserved, high-disparity populations in topics that relate to health (Baezconde-Garbanati et al., 2014; Frank et al., 2015; Kubicek et al., 2015; McNeeley et al., 2019).

- One way to establish trust is for academic institutions to listen and learn from these communities. Then, we address what the community believes are its most pressing health priorities.
- Trust takes long-term investment and commitment.
- Partnering with trusted members in the community and engaging them as messengers of health-related information (combatting misinformation) is critical. Partners include:
  - Religious leaders and the faith community
  - Advocacy groups
  - Trusted community leaders, organizations, and health and social service providers

Addressing health disparities in communities that are underserved and underrepresented requires multiple approaches and communication strategies. Activities may include storytelling in familiar formats, to counter misinformation with evidence-based, health promoting information.

Chapter Conclusion

The vignettes presented in this chapter illustrate key challenges, practices with potential for success, and opportunities for more positive experiences in community-partnered research. This is only a sampling of the large body of work. It is our common responsibility to learn from the lessons of the unprecedented global COVID-19 pandemic and other cultural shifts over the past 10 years to partner to investigate, innovate, educate, and legislate towards better health.

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Appendix 5: Accessible Descriptions for Complex Graphics

Figure 5.1—Knock Out Cancer Educational Infographic

Figure 5.1 Figure 5.1 is an infographic titled Knock Out Cancer! Talk to your doctor about your risk today. Large print states:

- **Wham!** Colorectal Cancer. Primary Care Provider or Gastroenterologist.
- **Bang!** Esophageal Cancer. Primary Care Provider or Gastroenterologist.
- **Zap!** Kidney Cancer. Primary Care Provider, Nephrologist, Urologist.
- **Blam!** Lung Cancer. Primary Care Provider or Pulmonologist.
- **Pow!** Oral Cancer. Primary Care Provider, Dentist, Periodontist, Oral and Maxillofacial Surgeon, Otolaryngologist. Speech-Language Pathologist.
- **Boom!** Prostate Cancer. Primary Care Provider or Urologist.

The bottom of the infographic states: Patient Voices Fights Cancer. For more information about each cancer, visit: https://patientvoicesbuffalo.com/fights-cancer/

◀ *Return to Figure 5.1*

Figure 5.2—The Community Engagement Studio Structure, from Joosten et al. (2015)

Figure 5.2 is a flow chart with two pathways the CE Studio Team can take, one for a researcher and one for stakeholders (currently referred to as key partners, replacing the word "stakeholder"). The steps are:

Request for CE Studio

CE Studio Team reviews request and follows the researcher or stakeholders path

For the researcher the path includes

- Clarify researcher questions
- Coaching on engaging non-researchers
- Create stakeholder friendly presentation

For stakeholders, the path includes

- Identify a pool of stakeholders through community organizations and clinical practices and create "expert panel"
- Pre-meeting orientation

Both paths converge in a facilitated meeting that includes

- Researcher presentation
- Stakeholder feedback
- Co-learning experience
- Process evaluation

This converged path ends in a summary of oral and written stakeholder feedback.

Researcher outcomes include

- Changes in knowledge and attitudes
- More patient and community-centered approach to the design, implementation, and dissemination research

Stakeholder outcomes include

- Perception of value relevance and acceptability
- Changes in knowledge and attitudes about research

◀ *Return to Figure 5.2*

CHAPTER 6: UNDERSTANDING SOCIAL NETWORKS IN COMMUNITY ENGAGEMENT

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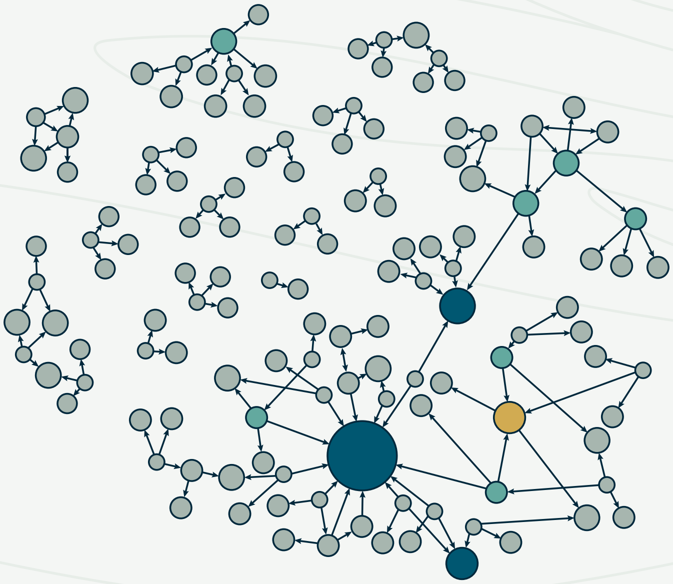
People connect to each other in many ways, including through familial ties, friendship, employment, cultural activities, religious affiliation, hobbies, and political activities. These "social networks" greatly influence people's health and are important to every aspect of community engagement. The growth in electronic social media (e.g., YouTube, Facebook, Twitter, WhatsApp, and Snapchat) has extended our ability to connect with existing networks. It also increases our ability to create new networks. For these reasons, we devote an entire chapter to the role of social networks in community engagement. In this chapter, we define social networks, explain their importance for health and community engagement, and provide suggestions regarding how to understand and engage with them. We conclude our chapter by focusing on two specialized topics: 1) social media as a platform for social networks and 2) communities of practice that receive support from grant programs, professional associations, and other entities.

What are Social Networks?

In its simplest form, a social network is a set of individuals or collections of individuals connected in a pattern of relationships. Social networks reflect interpersonal behavior, such as talking, paying attention to what others are doing, asking for or giving advice, or corresponding or messaging with each other. In this way, social networks are usually informal (often organically developed) rather than formal relationships. Figure 6.1 is a sociogram depicting relationships among individuals to map the social network. The social network in this case is directors of nursing homes in Canada as measured by a survey in 2016.

Figure 6.1. A Social Network among the Directors of Nursing Homes in a Canadian Province



As Figure 6.1 shows, formal and informal networks can influence each other (e.g., a formal professional association of nursing home administrators can lead to informal conversations between them). We use both kinds of networks in community engagement. Thus, we use the term social networks to refer to both formal and informal networks. However, social networks are dynamic, and their designation as networks is a characterization by observers and not necessarily how people in the networks think of themselves. We can think about networks as a whole: How many people are in the network? How do they interact? And so forth. We can also think about networks from the point of view of individuals: What are the networks an individual is in? Who in the network are they connected to?

The Value of Social Networks in Community Engagement

Our social networks partially shape health conditions. Who we are in contact with influences what we do (or do not do) and what we know. The work of Burt (1987) and Christakis and Fowler (2013) has been formative in developing social contagion theory. This theory describes how networks shape people's attitudes and behaviors. Their research—which is not without controversy (Lopez, 2008; VanderWeele et al., 2012; Wasserman, 2013)—suggests that health conditions and behaviors, including obesity, smoking, alcohol consumption, drug use, and depression, spread within networks.

Other research addresses how social networks affect social capital and social support, which can affect health and well-being. Social capital refers to "features of social organization such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit" (Putnam, 1995, p. 66). Social capital affects health through its impact on the human, material, and informational resources people have available to improve their health. These include money, connections to health professionals, and influence over health-related policies and practices. Social support is the help and encouragement that we get from people in our lives. This support can provide health-related information, resources that affect health (like money, food, or a place to sleep), motivation to take care of one's health, resilience in the face of stress, and companionship for health-promoting behaviors like walking or going to the gym (House et al., 1988; Zilberberg, 2011).

Working with, enhancing, or linking existing social networks—or building new ones—can therefore be a way to improve health. One example is the "No Longer an Island" project. In this project, a study team used peer support groups, community outreach, media campaigns, and a community organization network to strengthen social networks and increase social support for African American men. Their research demonstrated a drop in perceived stress (Harley et al., 2020).

However, the ties that provide social support do not always improve health. In addition to the social contagion described by Christakis and Fowler (2013), other ways exist in which social interactions can have a negative effect on health and well-being. Results from a study of networks of seniors in rural South Africa (Moore et al., 2018) painted a complex picture. Network members living together in households may result in friction and poorer health outcomes. The authors noted that such contradictory findings are not unusual in their study population. They stressed the importance of understanding the specific content of social ties, such as the possibility that they involve social control. Furthermore, social networks can be sources of misinformation about health, including conflicting health advice from media, government, and fake news sources (Goodyear et al., 2021).

Social networks can disseminate new information and new practices, intentionally or not. The "diffusion of innovations" theory (Rogers, 2003) provides a conceptual framework for understanding how social networks can help in the spread of new information and practices. This theory highlights the characteristics of social networks, such as the role of opinion leaders. Opinion leaders are individuals and organizations perceived by others to be trustworthy, expert, and believable. Among the discoveries that social networks can help spread are ways to improve health, such as:

- Lifestyle changes, such as starting new behaviors or getting support or information to end old ones
- Use of new health care services
- Use of technology, like supportive phone apps

Appreciating the key role of social networks in spreading discoveries is a hallmark of diffusion theory (Dearing & Cox, 2018).

An example of how social networks spread discoveries comes from the Community Health Coalition (CHC) in Durham, North Carolina. The CHC is a small nonprofit started by a local physician. The CHC distributes health tips once a month to area churches. The churches include this information in their newsletters, in the service, or in health ministries. Linking to church social networks allows the CHC to reach more people faster than one by one. Also, the messages about health come from trusted ministers or church members instead of unknown health care representatives. In a different example, Chung et al. (2021) found that a network of local health departments asked each other for advice and information to improve the health of their communities (Chung et al., 2021).

In addition to being a critical factor in population health, building on social networks can facilitate the building of partnerships. For example, Brewer et al. (2020) began their work developing a COVID-19 emergency preparedness plan by administering a needs assessment survey to their existing network of African American churches. However, community engagement practitioners should also recognize the limitations of network-based engagement approaches. For example, one research team that engaged churches to reach African American community members with diabetes realized that they needed to go beyond church networks to connect with populations with the fewest existing resources for managing their disease (Silberberg et al., 2020).

The engagement process can also result in the development of new networks between institutions and the community or within the community itself. For example, a study of Medicaid funding for tenancy support services initiated by a homeless services advocate brought together homeless service providers and advocates, researchers, mental health service providers, government agencies from two states, program beneficiaries, and national experts. Some of the partners continued to work together when the project was over, without the involvement of the original team (Silberberg, Biederman, & Carmody, 2019).

Building new networks or strengthening existing networks may be a goal of community engagement because the right networks can improve the effectiveness and sustainability of programs. Sometimes the design of these networks brings together groups that may be unaware of possible collaborations. For example, multisector collaboration is critical for addressing social areas that affect health such as bringing school officials together with health professionals to make school lunches more nutritious, or connecting health care providers and employers who share a common interest in having a healthy workforce. The concept of "communities of solution," originally described in the 1967 Folsom Report, suggests that health problems cross not only sectoral divides, but also political, municipal, and other jurisdictional boundaries. Proponents of the communities of solution approach argued for the need to link the various communities that are relevant for addressing a specific health need (Folsom Group, 2012).

One way to create new networks is to build coalitions (see Chapter 1). Effective coalitions are examples of social networks that combine diverse expertise, resources, and time to produce outcomes that surpass those achieved individually. This strategy includes building multisector collaboration. Coalitions can consist of organizations, concerned citizens, community champions, volunteers, and key advocates or collaborators. Members can bridge the gaps between social groups within a community. Organizations and individual members can combine resources, share information, refer services, and coordinate delivery systems of various health initiatives. Differing perspectives within the coalition can increase creative solutions for the communities' specific needs. Together, members can co-develop logic models and action plans that are most relevant and effective for their community. In Bridging Silos, Korfmacher (2019) described how a coalition formed in Rochester, New York to address lead in paint from old houses. The coalition helped the public health mission of reducing lead exposure.

The example of church-based social networks, above, illustrates that the pursuit of health equality requires coalitions to recognize who is included in networks and who is left out, then countering those excluded by designing inclusive networking strategies or developing a secondary network. Networks develop within large sociopolitical constructs, which can shape the network. For example, a history of discriminatory policies and practices in the United States has resulted in segregation of neighborhoods, houses of worship, and other forms of association that are platforms for social networks. Coalitions must recognize such impacts when deciding which networks to engage and how. Otherwise, relying on social networks as a tool of health promotion and community engagement can reinforce existing social divisions and inequities.

Understanding Social Networks

Understanding networks can help during all phases of community engagement for health initiatives. For example, thinking about networks early on can help determine which individuals or organizations will be most effective at identifying community problems and potential solutions (Valente et al., 2015). In some communities, people's place of worship is the institution to which they are most tightly linked. In others, family ties dominate. In still others, schools or workplaces are the best way to reach people. Understanding networks can also help teams decide how to strengthen or expand networks to improve effectiveness. Understanding networks can also help determine how to mobilize communities to implement initiatives effectively. Community engagement practitioners can also study networks to see if an initiative was successful at promoting and sustaining increased collaboration.

To understand existing networks (of individuals, organizations, etc.), practitioners may use simple techniques such as soliciting information from individuals about their networks (both in-person and virtual) and turning those into drawings (McCarty et al., 2007). Other techniques include participatory network mapping. For example, the Net-Map tool (Schiffer & Hauck, 2010), developed to support work in Ghana, creates participatory network maps using simple large sheets of paper, post-its, pens, figures, and flat discs that represent influence.

Social network analysis (SNA) is a formal approach to understanding social networks that generates statistics about a network and its members. For example, network "density" is the proportion of all possible relationships that exist. "Node centrality" is the importance of a particular member to the network. Practitioners also use SNA to generate visual network maps that provide information about the characteristics of network members and the relationships among them and how they change over time. Tools such as the PARTNER platform can help (Visible Network Labs, 2022).

Practitioners can use SNA to assess networking needs at a given moment. For example, in support of the Kate B. Reynolds Charitable Trust's Healthy Places initiative, Dupre et al. (2016) conducted SNA of the relationships among people in rural North Carolina counties who were working to improve community health and well-being. The findings suggested a need to better connect people in the health sector with people in other sectors.

Practitioners can also conduct SNA before and after a community engagement initiative. In this case, SNA can determine if there has been an improvement in the kinds of connections that the initiative built. Recently, a number of scholars have used SNA to identify strengths and areas for improvement in community-campus partnerships for health (Cabrera et al., 2020; Franco et al., 2015; Luque et al., 2011). For example, the Tampa Bay Community Cancer Network (TBCCN) developed a sustainable, community-based partnership network focused on the goal of reducing cancer health disparities in the Tampa Bay, Florida, area. Partners completed SNA before and after their community-engaged work. The findings suggested that after work was completed, there were an increased number of connections and interactions among network partners. It also showed decreased dependence of other organizations on the cancer center, making the network more sustainable and stable than it had been when one organization was central to its operation (Luque et al., 2011).

Some tools for understanding networks are more complex and require more resources than others. Teams should carefully consider which tools are most appropriate for a specific project, given what they are trying to accomplish and the resources they have available.

Social Media and Community Engagement

Virtual social networks—both formal and informal—have been multiplying over the past 10-15 years. The advent of social media platforms enables individuals to gather and share ideas, experiences, and knowledge regardless of their geographic closeness (Patten et al., 2021). The importance and relevance of these virtual social networks became particularly evident in 2020 during the COVID-19 pandemic. The physical distancing recommended to reduce exposure to the virus led people to rely on social media for information and relationships (Bowden-Green et al., 2021; Goodyear et al., 2021; Pérez-Escoda et al., 2020).

Social media, a term referring to many ways by which people share ideas, interact, develop content, and exchange information within virtual communities, has become widespread. Social media informs how we live, work, vote, and play. In a world with nearly 8 billion people, it is estimated that, in 2022, more than 4.5 billion worldwide used social media. This number has grown significantly since the COVID-19 pandemic and may increase to nearly six billion in 2027 (Statista, 2024).

While many platforms have global reach, YouTube, Facebook, X formally known as Twitter, Instagram, and WhatsApp are among the most popular. Monthly users of these platforms are estimated to be in the billions (Pew Research Center, 2021b, 2021c). Communities can use social media platforms to promote, build, mobilize, and track social networks. Communities can expand their reach using social media platforms, helping with multidirectional and global communication. In addition, they provide new forums in which to raise issues, exchange ideas, engage a larger community, and promote action. Each virtual platform has several assets, including:

- Its own cultures and social dynamics
- Different intergenerational appeal and participation
- Structures and users form and shape the platform
- Unique opportunities for using communities to address various concerns

The Potential of Social Media

A community partner and US Public Health Service employee at a community event. *ATSDR, 2016.*

Social media has proven to be effective for engaging a large and diverse group of people. This includes individuals with rare diseases and people who researchers were not able to reach through traditional means. While some communities exist in either an in-person or virtual context, other communities exist in both. The same concern about social networks reinforcing social divisions and inequities pertains to virtual networks.

Social media provides a forum for exchange of ideas and discussions that differs from in-person interactions. Anyone who has access to the platform can participate passively (reading/reviewing posted comments/material) or actively (posting and responding to others' posts). People do not need to respond immediately. They can take time to review the thread of a discussion and initiate new threads to further expound upon points. Thus, social media platforms provide opportunities to reframe questions as the discussion evolves or group priorities shift (Connor, 2009). Of note, some online networks are private, and approval is needed before participants can access the forum. In addition, social media can generate a discussion archive that is useful for revisiting (and for new members to learn about) opinions, information, and collective history. The manner in which the community uses social media in the early stages of engagement might indicate the capacity for successful engagement in that community.

Generally, a broader group of participants can be engaged using social media than through traditional means. This helps establish collective positions and strategies. Participants could include those with different levels of investment in the topic and represent a variety of roles. Of note, participants can remain anonymous using an online persona or avatar. Using the COVID-19 pandemic as an example, an online community could include those directly affected, partners and other family members, health and human service professionals, and members of the larger community. Social media used by healthcare professionals and patients has strengthened (among other things) management of treatments (Litchman et al., 2018), infection prevention (Madhumathi et al., 2021), research recruitment (Lunn et al., 2019), intervention development (Jones et al., 2019), and advocacy efforts (Scott & Maryman, 2016).

Social media plays a role in building and sustaining networks by creating forums, helping with communication, encouraging social exchange, coordinating activities, and providing entertainment. Social media can mobilize individuals and organizations and can help sustain engagement and commitment. Social media also enables individuals or groups to offer and receive social support and identify emerging challenges and concerns. An effective online community should have objectives and goals specific to online community-building. This includes tools to facilitate engagement, feedback, and member-to-member interaction. The online community should also have processes to identify and manage conflict and determine how to track progress (Bacon, 2012). Moreover, social media can help build trust by providing venues that facilitate transparency and openness. Those seeking to engage with communities through social media can identify and work with existing communities, engaging through developing and strengthening their online presence. Or, if the community is not yet established, they can support the creation of a virtual community.

Previous studies have documented efforts to engage community members in research using social media platforms (Tang et al., 2019). One study used a popular social media platform to engage participants in an intervention aimed at improving the uptake of HIV/syphilis self-testing (Wu et al., 2021). The research team placed advertisements on social media platforms to recruit study participants. They used another social media page that enabled participants to order HIV/syphilis self-test kits for themselves, as well as members of their social networks. Another research project took a different approach by identifying opinion leaders (Mommy Bloggers) within a social media platform. The researchers partnered with the bloggers to disseminate breast cancer and environmental risk information to mothers (Wright et al., 2019).

Cautions on the Use of Social Media

Many cautions about social media are similar to those for any community engagement activity (Bacon, 2012). When appraising face-to-face interactions, we ask, are the responses honest and will people have time to participate? We need to ask those questions about the use of social media, too. However, use of social media raises additional concerns about who is actually participating and whether they are who they represent themselves to be. Building trust is essential for community engagement, and networking through social media alone is unlikely to achieve the level of trust needed for collective action. Social media may be better viewed as supplementary rather than as a substitute for in-person interactions. This may be most relevant in the early stages of community engagement. Furthermore, social media is not an inexpensive alternative to the in-person building of relationships. Like any community engagement effort, use of social media for communication engagement will take time and resources (Connor, 2009). As noted by Scott and Maryman (2016), social media alone is likely not enough for advocacy. They suggest that more traditional organizing strategies may also be necessary (Scott & Maryman, 2016). Overall, it is important to understand the modes of communication employed by the community of interest and then use those modes.

Time is a particular concern for the person who plays the crucial role of moderating a social media forum (although not all forums will require a moderator). It is the moderator's job to demonstrate that someone is monitoring information sharing and dissemination, keep the discussion developing, and recruit and retain members. There are many ways to undermine an online community. It is the moderator's job to enforce the "rules of engagement." Once established, a forum—formal or informal—requires regular attention. Given the pace of interactions in the social media environment, moderating a forum may require visiting the site several times a day (Bacon, 2012).

Relatedly, people may use social media to spread misinformation (Chou et al., 2018, 2021; Wang et al., 2019). Investigating sources is critical to prevent reporting wrong or misleading information. According to a recent Pew Research study, 86% of respondents said they get their news from a smartphone, computer, or tablet (Pew Research Center, 2021a).

We have not included recommendations about specific products in this chapter because products evolve. Although we address how people use social media, the question of whether or when it is appropriate to use specific social media depends on the individual project, available resources, and the appropriateness of the tool for the particular community. Given the resources necessary to involve social media, it would be a mistake to try to be "everywhere" online. Engagement is iterative. Organizations should be selective, determine which media the community of interest is already using, and ask the community what approaches should be used and at what time in the engagement process. Like all decisions about community engagement strategies, deciding whether to use social media is up to the community.

Communities of Practice

Thus far, we have focused on social, interpersonal relationships and connections among members of a community and networks created to address needs in a specific community. Communities of practice (COPs), in many respects, are a layer on top of those social networks, almost like a network of networks. Groups of people with a particular work role or expertise who come together around a shared interest in a topic, subject matter, professional specialty, or problem are a COP. People join these communities as a way to learn more, share their knowledge, and contribute to advancing work in that topic or discipline (Garfield, 2018).

Funders have been establishing their own social networks of COPs, such as the Clinical and Translational Science Awards (CTSA) Program, Prevention Research Centers (PRC), and Partnerships for Environmental Public Health (PEPH). These COPs advance community engagement approaches, accelerate research translation, and improve public health. They foster ties among research teams, provide access to resources, and promote a sense of social attachment within the programs.

A timely example of COPs and their vital importance to community engagement is the Community Engagement Alliance (CEAL) Against COVID-19 Disparities program. The NIH launched this program to "provide trustworthy, science-based information through active community engagement and outreach to the people hardest-hit by the COVID-19 pandemic, with the goal of building long-lasting partnerships as well as improving diversity and inclusion in our research response to COVID-19" (National Institutes of Health, 2023a). NIH funds Individual CEAL teams across the United States. The teams build on existing community partnerships and establish new ones. The CEAL program creates a national COP among the grantees and their partners. In this context, the individual teams come together within the COP to learn, share, and advance approaches collaborate with communities. In less than a year, this COP helped to advance communication approaches across the United States. The COP established online a list of resources to enable health care professionals, public health officials, and community leaders to effectively discuss COVID-19 and the vaccines (National Institutes of Health, 2023b).

Similarly, the NIEHS established the Partnerships for Environmental Public Health (PEPH) as a network program. In this COP, NIEHS brings together its various grant programs and research teams with a shared commitment to community engagement and environmental public health. PEPH enables grantees to move past areas of specific focus into a collaborative environment. Grantees share ideas and knowledge about common issues, topics, and approaches. PEPH teams address issues such as evaluation measures, reporting research results, and environmental health literacy. The PEPH COP has helped to inform environmental health literacy through face-to-face meetings, webinars, and other grantee interactions. By facilitating interactions among PEPH members, the COP was able to accelerate the professional discussion and uptake of environmental health literacy, as evidenced in the peer-reviewed literature.

The 100 Million Healthier Lives global movement also demonstrates the value of a COP. Convened by the Institute for Healthcare Improvement (IHI), this COP works among communities to bring about health, well-being and equity (Institute for Healthcare Improvement, 2023). IHI has highlighted 10 case studies that illustrate the benefits of this approach (Institute for Healthcare Improvement, 2020). It is important to remember that members within a COP also belong to their own social networks. This reach can make them vital to community engagement efforts to inform and influence place-based and virtual social networks to improve health.

Chapter Conclusion

Social networks engage in ways that are positive or negative for the effectiveness of initiatives to improve health and health equity. It is critical to take the time to understand the advantages and disadvantages of networking options. These include social media options that may relate to any specific effort. Changes in social networks can also be an important metric for evaluating community engagement.

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CHAPTER 7: ADVANCING EQUITY THROUGH COMMUNITY-PARTNERED PROGRAM EVALUATION

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This chapter provides an overview of the principles of program evaluation. It is important to evaluate both community-engaged initiatives and their base partnership. This chapter presents:

1) **A definition of evaluation and the standards that govern it**
2) **Evaluation phases and processes**
3) **Approaches to evaluation that are relevant for community-engaged initiatives and community-partnered evaluation**
4) **Specific evaluation methods**
5) **Challenges to ensure effective evaluation**

Community-partnered research evaluation and strategies to include people involved in or affected by programs are major themes in this chapter. We included methodological approaches and recommendations and examples. Implementation of these recommendations should align with the American Evaluation Association Guiding Principles detailed later in this chapter (American Evaluation Association, 2018).

Program Evaluation

Program evaluation is "the systematic collection of information about the activities, characteristics, and outcomes of programs, for use by people to reduce uncertainties, improve effectiveness, and make decisions" (Patton, 2008, p. 39; Posavac, 2015). This definition guides us toward including the goals, concerns, and perspectives of the program partners. Partners should identify program priorities and what constitutes "success." Partners should also identify the data sources that could serve to answer questions about acceptability, possible participation levels, and short- and long-term impact of proposed programs.

This chapter, along with other chapters, uses the term "partner(s)" to denote key influencers, community leaders, and/or anyone interested in or engaged with the evaluation. This use of partners replaces the common term "stakeholders." The chapter follows the CDC's Health Equity Guiding Principles for Inclusive Communication (Centers for Disease Control and Prevention, 2023). The CDC document encourages the use of language that is non-judgmental and that promotes acknowledgment of and intentions to address power differences among groups. The community as a whole and individual community groups are both key partners for the evaluation of a program. Community-partnered evaluations identify the relevant community and establish partner perspectives for appropriately assessing activities and opportunities for improvement.

This approach is part of measurement of the program. It also is part of the ways in which diversity, equity, and inclusion reflect community priorities for sharing information and power in planning, implementation, and assessment. These types of evaluations ensure involvement of the appropriate people or organizations. These evaluations also determine how partners are involved, if they have significant input, and how they develop and sustain engagement.

Program Evaluation: Defined and Distinguished from Research

Program evaluation uses the methods and design strategies of traditional research. However, research is a systematic investigation designed to develop or contribute to generalizable knowledge (MacDonald et al., 2001; Owen, 2020). Evaluations are also systematic (e.g., data collection, analysis, and interpretation). However, where research studies may occur in controlled environments, community engagement programs (and their evaluation) take place in the "real world." The goal of evaluation is not to prove but to improve programs and services (Stufflebeam, 2007). Program evaluation aims to incorporate differences in partner values and perspectives from the beginning. It may address multiple types of questions and seeks to create results for different audiences (National Center for Chronic Disease Prevention and Health Promotion, 2011).

Types of Evaluation

There are in five general types of evaluation by intended use: formative, process, summative, outcome, and impact (Table 7.1).

Table 7.1 Types of Evaluation

EVALUATION TYPE	DESCRIPTION
Formative Evaluation	Provides information to guide program improvement
Process Evaluation	Examines whether program delivery to targeted recipients is as intended
Summative Evaluation	Determines if the program met its goals and objectives
Outcome Evaluation	Examines whether the program resulted in expected changes in observable conditions of a specific population, organizational attribute, or social condition
Impact Evaluation	Examines achievement or progress toward the program's long-term goals

Formative and process evaluation: Formative evaluation provides information to guide program improvement. Process evaluation determines whether the program delivery to the targeted recipients is as intended (Rossi et al., 2018). Evaluators conduct formative and process evaluations as the program is undertaken.

Summative evaluation: Summative evaluation informs judgments about whether the program worked (i.e., were the goals and objectives met?). It requires making clear the criteria and evidence used to make "summary" judgments.

Outcome evaluation: Outcome evaluation focuses on whether the program resulted in expected changes in observable conditions of a specific population, organizational attributes, or social conditions.

Impact evaluation: Impact evaluation examines progress toward or achievement of the program's long-term goals.

Evaluators conduct summative, outcome, and impact evaluation at the end of a program when it has been ongoing for a substantial period of time (Rossi et al., 2018). For example, assessing the strategies used to implement a smoking cessation program and determining the degree to which it reached the intended population are process evaluations. In contrast, an outcome evaluation of a smoking cessation program might examine how many of the program's participants stopped smoking. Impact evaluation might assess how successful the program was in meeting a goal, such as reduction in morbidity and mortality associated with cardiovascular disease from a smoking cessation program (Rossi et al., 2018).

Program evaluation has increasingly become an essential process for demonstrating program accountability and proper stewardship of resources, especially among government-funded programs. The 2017 Report of the Commission on Evidence-Based Policymaking (U.S. Department of Health and Human Services, 2017) and the Foundations for Evidence-Based Policymaking Act (2018) highlight the increased importance of using program evaluation for accountability measures.

Several institutions have identified guidelines for effective evaluation. In 1999 (updated in 2012 and 2017), CDC published a framework to guide public health professionals in developing and implementing a program evaluation (Centers for Disease Control and Prevention, 1999, 2009, 2012, 2017). The motivation for the framework was to help integrate evaluation into public health programs. The framework focuses on six components. While evaluators can use these interdependent components in any order, the earlier domains provide a foundation for later areas. They include the following:

- Ensure that all partners are invested in the program and will become engaged early in the evaluation process.
- Fully describe the program's needs, expected outcomes, activities, resources, stages of development, context, and logic model, and clearly identify its goals and objectives.
- Design the evaluation to be useful, doable, ethical, and accurate.
- Gather credible evidence to inform and determine program results and evaluation recommendations. Sources of evidence could include people, documents, and observations.
- Demonstrate how the conclusions follow from the results and how they relate to participants' standards and values.
- Deliberately share and use the lessons learned.

The American Evaluation Association, whose mission includes improving evaluation practice and methods, increasing evaluation use, and promoting evaluation as a profession, created the Guiding Principles for Evaluators (American Evaluation Association, 2018). The guiding principles aim to center evaluators on ethical behavior that is essential to conducting evaluations. The five principles include the following:

1) **Systematic Inquiry: Evaluators conduct data-based inquiries that are thorough, methodical, and contextually relevant.**
2) **Competence: Evaluators provide skilled professional services to partners.**
3) **Integrity: Evaluators behave with honesty and transparency to ensure the integrity of the evaluation.**
4) **Respect for People: Evaluators honor the dignity, well-being, and self-worth of individuals and acknowledge the influence of culture within and across groups.**
5) **Common Good and Equity: Evaluators strive to contribute to the common good and advancement of an equitable and just society.**

Together, the *Principles of Community Engagement* and the CDC program evaluation framework established standards provide a general perspective on the characteristics of an effective evaluation. All identify the need to be practical with the goal of determining the effectiveness of a program. Additionally, program evaluation standards are the tools evaluators use to promote cultural competence and advance the understanding of the cultural context of a program and its evaluation (Gill et al., 2016).

Intersectionality: A Lens and Practice Toward Community-Partnered Evaluation

Evaluators who recognize a diversity of views, perspectives, and experience can improve evaluation and ensure the measurement of important constructs and concepts. Factors to consider include valuing diversity, between and within groups, health or health care equity, and inclusion. Inclusion requires acknowledging how overlapping identities (e.g., sexual, gender, racial/ethnic minority identities, geography [rural vs. urban]) contribute to the disproportionate burden of inadequate health care and related health disparities (Bowleg, 2012). The Intersectionality framework holds promise for implementing fair community engagement in evaluation planning and implementation (Bowleg, 2012). It assumes that individual-level characteristics of identity do not, in isolation, shape health outcomes. These characteristics are multilayered, intersect, and come from experience within contexts, systems, and power structures related to relative privilege or oppression (Larson et al., 2016). Evaluators can apply the framework to achieve more equal participation and engagement of historically marginalized communities disproportionately experiencing poorer health care outcomes. Understanding how experiences of social and political inequities translate to barriers to care can result in better designed programs with evaluable measures that matter (Gkiouleka et al., 2018; Hankivsky et al., 2014).

Health inequity experiences include but are not limited to discrimination or implicit bias. When community-partnered evaluators view health inequity experiences through the intersectionality framework it may explain why interventions are effective for some communities and require adaptation or are ineffective in others. This approach shows the evaluation's value in advancing social justice and health equity. Evaluators use this framework with both qualitative and quantitative study methods, which we describe in the sections that follow. Evaluators also use the framework with diverse community groups to develop more community-informed planning of interventions or programs (Ghasemi et al., 2021). Important and welcome tensions arise among evaluation team members when applying the Intersectionality framework, including:

- The justified discomfort of some in discussions of social injustice
- Diversity of thoughts or disciplines (lived experiences, training, and exposure)
- Reaching consensus or agreement through thoughtful decisions related to "meaningful inclusion" versus tokenism (Kelly et al., 2021)

Practical tips, tools, and guides to apply this framework reflect global practice in public health, research, policy, and health care, among other fields (Atewologun, 2020; The Opportunity Agenda, 2017). While the fundamental evaluation standards, principles, and approaches are essential for understanding and practicing community engagement, corresponding community-partnered processes and assessment priorities are important for advancing equity. The sections that follow detail both.

Evaluation Phases and Processes

The program evaluation process includes four phases that we describe in this section: planning, implementation, completion, and dissemination/reporting (Table 7.2). Each phase has unique issues, methods, and procedures.

Table 7.2 Evaluation Phases

EVALUATION TYPE	DESCRIPTION
Planning	Involves outlining the evaluation approach through: • Determining feasibility of evaluation • Identifying community partners • Specifying evaluation questions • Determining short- and long-term goals
Implementation	Examines whether the program is: • Successfully recruiting and retaining intended participants • Using training materials that meet standards for accuracy and clarity • Adhering to projected timelines • Coordinating efficiently with other ongoing programs and activities
Completion	Assesses changes in target population. It determines the extent to which outcomes are attributable to the program and examines long-term impact of the program
Dissemination/Reporting	Ensures that evaluators report and disseminate results to all appropriate audiences

Planning

The relevant questions during evaluation planning and implementation involve determining the feasibility of the evaluation, identifying community partners (among others), and specifying short- and long-term goals. Questions evaluators ask during evaluation planning should consider the criteria for determining the need for the program and the program's conceptual framework or underpinnings. In other words, is the program gathering the right information to ensure it is optimally working within the community context?

Defining and identifying partners is a significant component of planning. People or organizations that have an interest in or may benefit by the program evaluation are all considered partners. They can be people who work in program operations, serve the program, perceive effects from the program, or are primary program users. The inclusion of community partners across evaluation phases helps build support for the evaluation. It also increases its credibility, provides a participatory approach, supplies the perspectives of many participants and partners, and should identify the most appropriate partners who are not yet represented in evaluation (Rossi et al., 2018).

For example, in the evaluation of a program to increase access to healthy food choices in and near schools, potential partners could include store merchants, school boards, zoning commissions, teachers, parents, and students. Partners are an important resource for identifying the questions a program evaluation should consider. They also help select the method used, identify data sources, interpret findings, and implement recommendations (Agency for Toxic Substances and Diseases Registry, 2018; Centers for Disease Control and Prevention, 1999, 2012).

Once evaluators identify partners, they collaboratively need to create a strategy to engage them in all phases of the evaluation. Ideally, partner engagement takes place from the beginning of the project or program or, at least, the beginning of the evaluation. The partners should know that they are an important part of the evaluation. They will consult on the evaluation on an ongoing basis throughout its development and implementation. The relationship between the partners and the evaluators should involve two-way communication. Partners should feel comfortable initiating ideas and suggestions. One strategy to assure partner comfort is to establish a community advisory board (CAB) to oversee program and evaluation activities in the community. Regular meetings of the CAB are essential for building group identity and confidence in articulating the mission and scope of the partnership. This will help set expectations, which will keep the energy and culture of the partnership moving forward. Later in this chapter, we provide an example that details the assessment of prioritized values and processes related to this type of community-partnered structure.

Community participation in program evaluation helps evaluators establish the validity of program measures and approaches and can increase the likelihood of getting the desired effects (Hood, Hopson, & Kirkhart, 2015). If a goal of program evaluation is social reform, community members must feel empowered to "bring their agency" (take ownership) and engage in partnership with clinicians and academics. Evaluators should be sensitive to community partners that in disenfranchised or marginalized communities. The community partners may perceive a power imbalance, which may undermine the partnership, limit trust, and inhibit change. In this construct, institutional actors engage in a passive model of helping community members. The community members receive and respond to the program rather than serve in equal positions (Solomon, 1976).

The concept of co-creation has outgrown this model (Greenhalgh et al., 2009). One must know and respect one's partners. This includes understanding the systems that influence the ways in which partnered individuals "show up." Evaluators have a responsibility to be transparent about their dependence on community members to get their jobs done. Evaluators must acknowledge that power dynamic to partner with communities in good faith.

Implementation—Formative and Process Evaluation

Evaluation may examine whether the program is successfully recruiting and retaining its intended participants. Evaluation also may assess how the program is using training materials that meet standards for accuracy and clarity, adhering to projected timelines, coordinating efficiently with other ongoing programs and activities, and meeting applicable legal standards. Evaluation could inform midcourse corrections to the program (formative evaluation) or shed light on processes (process evaluation).

Completion—Summative, Outcome, and Impact Evaluation

A program's outcome is "the state of the target population or the social conditions that a program is expected to have changed" (Rossi et al., 2004, p. 204). For example, when evaluating the effectiveness of empowerment-based education of diabetes patients, control of blood glucose was an appropriate program outcome (Anderson et al., 2009; Cortez et al., 2017). In contrast, the number of people who received a program service would not be an appropriate outcome unless participation represented a change in behavior (e.g., participating in a walking program). Similarly, the number of elderly housebound people receiving meals is not a program outcome. However, the nutritional benefits of the meals actually consumed for the health of the elderly, as well as improvements in their perceived quality of life, would be appropriate program outcomes (Rossi et al., 2018).

Program evaluation determines the extent to which outcomes are results of the program. If evaluators are evaluating a partnership, the contributions of that partnership to program outcomes may also be part of the evaluation. Once evaluators confirm the positive outcome of a program, later program evaluation may examine the long-term impact of the program. For example, evaluators may evaluate the outcome of a program designed to increase the skills and retention of healthcare workers in a medically underserved area. They could select the proportion of healthcare workers who stay for one year as a program outcome. However, this outcome would not represent the number of providers who participated in the training program. Reducing maternal morbidity and mortality might be an outcome that such a program would hope to affect in the long term (Mullan, 2009; Taylor & Nies, 2013).

Dissemination and Reporting

Evaluators need to develop a comprehensive and systematic dissemination strategy during planning of the evaluation. They should include guidelines in the plan, such as:

- Who will present results
- Guidance on disseminating results
- A results dissemination schedule (often on a rolling basis)
- Which audiences will receive the results
- Who the evaluators plan to include as authors or presenters

Dissemination should also include use of social media and social networks.

Dissemination of the results of the evaluation requires resources and partnerships, such as people, time, and money. It may be difficult for community members to find time to write reports or papers and make presentations amidst their other commitments (Flicker & Nixon, 2018; Parker et al., 2005). Non-scientific presentation development and dissemination is not traditionally taught or rewarded in academia. This may result in academic partners who do not want to spend time disseminating results in community contexts. Community-partnered evaluations create opportunities for community partners to develop dissemination products (community briefs, infographics, blogs, etc.) that are culturally appropriate and accessible. The emphasis should be on full disclosure (regardless of whether results are positive) and a balanced assessment so that results can strengthen the program.

Using Social Media in the Context of Community-Partnered Evaluations

As described in Chapter 6, communities may engage virtually or in person for purposes ranging from support and information sharing to agenda setting and advocacy. Evaluators can engage with online communities for various purposes. The most basic level is evaluating the community's engagement, such as:

- To assess a process measure (frequency or type of engagement)
- To evaluate the nature of the engagement (e.g., content of posts or discussion)
- To access the progress or achievement of group goals (e.g., products; group growth).

With any evaluation, members of the online community can help shape it. What do they think is important? What would they like to learn about?

Gathering evaluation data online requires the same safety protocols as with any data collection. If the evaluator is outside the community or intervention, trust presents additional challenges. Community leaders or the intervention team need to help the evaluator engage with the community. The evaluator needs to look for issues that could indicate lessening interest in the evaluation. At the beginning, those responsible for evaluation need clear guidance regarding the data. As with in-person data collection, evaluators judiciously use online data collection tools. Just because it is online, there is no less burden (e.g., adding questions or instruments will still be burdensome). Evaluators should consider factors such as accessibility of tools to avoid participation barriers. The vignette on the pages that follow details the experience of one community-partnered program and its evaluation of virtual program delivery.

Transitioning to Telehealth Mental Health Services during the COVID-19 Pandemic

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Evaluation Question or Issue

How do evaluators evaluate when an emergent situation arises? What do evaluators do when a sudden change of course is required, and they need to quickly disseminate information to the team to inform decision-making?

Challenge

The COVID-19 pandemic required shifting to remote mental health services for a population who is unhoused or with unstable housing.

Response

At the onset of the COVID-19 pandemic in New York City our community-based behavioral health program quickly made the move to telehealth. We ensured that staff members had access to various devices (laptops, tablets), platforms (Zoom, Microsoft Teams), and technology (Wi-Fi) to facilitate their work. We were able to adapt our evidence-based interventions to the online platforms. We developed an engagement model to ensure that staff members were in regular contact with their clients to encourage and foster attendance at upcoming sessions. The evaluation strategy then mirrored this response. This meant transitioning client feedback mechanisms including focus groups to online platforms. We made sure to include the voices of as many community partners as possible.

Promising Practice

We created "guide sheets" to help clients access the meeting platforms on their devices. We developed group norms that were specific to the virtual environment. These norms included how to work with people who may not be in a private environment and how people should participate when in those environments (for example, do not be on speaker phone). We adapted the evaluation to gather feedback about the transition to telehealth and the ways in which the program navigated challenges with technology and privacy. We gathered feedback from both clients and staff members to understand who we served, who we missed, what worked, and what could improve. We used the evaluation organizational learning feedback loop (Dodd & Meezan, 2009) worked to keep all community partners informed and engaged in rapid and responsive program decision-making.

Lessons Learned for Strengthening Community-Partnered Evaluation

Our program and larger organization rapidly moved to telehealth as a response to the pandemic. However, we did not have the time or ability to undertake important steps prior to implementation. As a result of our ongoing evaluation, we found the following to be critical to our future success in telehealth:

1) **Assessing staff members or client readiness to adapt to new platforms**
2) **Taking regular inventory of client technology and service access both generally and with regard to safely engaging in services in a way that protects private health information (PHI)**
3) **Emphasizing the important function of and need for in-person connection and social supports, particularly for group and behavioral health services. There is a need to develop and test strategies to mimic the in-person connection/experience**
4) **Considering the demographics of those accessing services: older, nonwhite, unstably housed or living in shelters. This population was less able to access the services once they transitioned to telehealth. We were also unable to follow-up with some members of this population.**

Take-Home Messages

While building a mental health telehealth structure is possible and scalable, it is not a viable solution for everyone. This is particularly challenging in a setting reliant on in-person engagement and support of people with unstable housing. It is critical to establish a rapid-response evaluation feedback loop that allows for input from key community partners at all levels (staff members, clients, and program and agency leaders). This loop allows for timely decision-making that does not compromise the integrity of the evaluation process or the program.

Approaches to Evaluation

Over the last two decades, program evaluation approaches have evolved. Contributions and perspectives of diverse partners increasingly inform many evaluation measures. This section provides an overview of different approaches contributing to these values and practices. This section also details considerations and challenges related to these approaches. Partners should reflect on the ways they organize collaborations, assess their partnership dynamics and values, and the history and duration of the program and the partnership. These, among other contextual factors, can help to determine the most appropriate evaluation approaches and methods.

Participatory Evaluation

Participatory evaluation can help improve program performance by:

1) **Involving key partners in evaluation design and decision-making**
2) **Acknowledging and addressing asymmetrical levels of power and voice among partners**
3) **Using multiple and varied methods**
4) **Having an action component so that evaluation findings are useful to the program's end users**
5) **Aiming explicitly to build the evaluation capacity of partners (Burke, 1998).**

Characteristics of participatory evaluation include the following (Patton, 2008).

- The focus is on participant ownership. The evaluation orients to the needs of the program partners rather than the funding agency.
- Participants meet to communicate and negotiate to reach a consensus on evaluation results, solve problems, and make plans to improve the program.
- Evaluators seek and recognize input from all participants.
- Evaluators emphasize identifying lessons learned to help improve program implementation. They also determine whether the program met target milestones.
- The evaluation design is flexible and determined (to the extent possible) during the group processes.

- The evaluation uses empirical data to determine what happened and why.
- Partners may conduct the evaluation with an outside expert serving as a facilitator.

An extension of this participatory evaluation philosophy and practice is Transformative Participatory Evaluation (T-PE; Cousins & Whitmore, 1998). While representing the same principles of Participatory Evaluation, T-PE prioritizes social change. Among its aims are to:

1) **Empower all partners through developing and respecting each other's knowledge and the relationship between knowledge, power, and control**
2) **Amplify the processes of the collaborative work and how evaluation takes place**
3) **Invite regular, critical reflection examining the social factors that influence the collaboration, as well as the individual and collective biases or understandings (Cousins & Whitmore, 1998).**

Goodman et al. (2019, 2020) used a Delphi process (a collective opinion process) in developing valid quantitative measures. These measures include eight essential elements to assess stakeholder engagement in research and the associations between engagement and research outcomes (Goodman, et al. 2019, Goodman et al. 2020):

1) **A focus on community perspectives and determinants of health**
2) **Partner input is vital**
3) **Partnership sustainability to meet goals and objectives**
4) **Fostering co-learning, capacity building, and co-benefit for all partners**
5) **Building on strengths and resources within the community or patient population**
6) **Facilitating collaborative, equitable partnerships**
7) **Involving all partners in the dissemination process**
8) **Building and maintaining trust in the partnership**

Empowerment Evaluation

The major goal of empowerment evaluation is to transfer evaluation activities from an external evaluator to the partners. Empowerment evaluation provides partners with tools and skills to evaluate their program and ensures that the evaluation is part of the planning and management of the program (Fetterman, 2012). Empowerment evaluation has three steps:

1) **Establish the mission**
2) **Take stock of the current status**
3) **Plan for the future**

Considerations and Challenges

Participatory and empowerment evaluation should address the possibility that others may view the evaluation as less objective because of the expanded scope of community-partnered evaluation. It should balance inclusivity of a broad spectrum of partners, some of whom may not have experience with the technical aspects of evaluation. In addition, it should find the time and resources needed to involve partners meaningfully and strategically. However, the benefits of fully engaging partners (particularly the community) throughout the evaluation outweigh these concerns (Fetterman et al., 1996, 2014).

Model for Collaborative Evaluations

The Model for Collaborative Evaluations (MCE; Figure 7.1) prioritizes 1) ongoing engagement between evaluators and partners; 2) strong evaluation design, data collection, and analysis; and 3) sharing and use of results with all interested parties (Fetterman et al., 2017). This approach is useful when the evaluator solely leads the evaluation but consistently consults the partners on aspects of the evaluation design and process (i.e., they work in collaboration to ensure the success of the evaluation; Fetterman et al., 2017, p. 10–11). The collaboration evaluation approach includes the following (Rodríguez-Campos et al., 2020).

Identify the situation: set the foundation of the collaborative evaluation. Implement steps to determine the situation, setting, and characteristics of the evaluation. Take the time for these activities, rather than relying on the perceptions of partners and/or the client. In this step, the evaluator identifies partners, logic model elements, and potential SWOTs (strengths, weaknesses, opportunities, and threats). The evaluator also establishes the evaluation scope (i.e., evaluation questions, work breakdown structure), and critical evaluation activities.

Clarify the expectations: ensure that everyone clearly understands the anticipated outcomes of the evaluation, their roles, the evaluation process, and the evaluation budget.

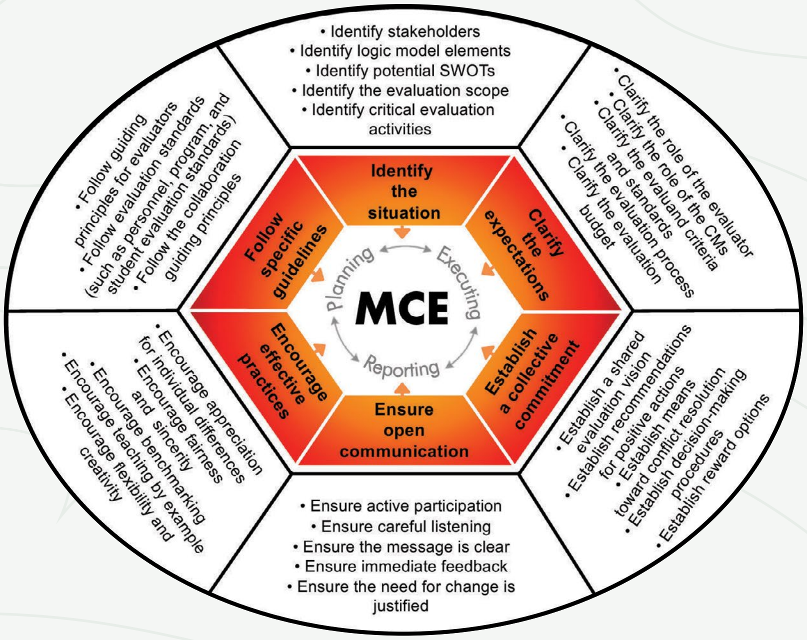
Establish a collective commitment: create a shared vision for the evaluation with a commitment to meeting the obligations of the evaluation with ethical discernment. This step establishes decision-making procedures, provides a means for resolving conflicts, and emphasizes the benefit for all that the evaluation will provide.

Ensure open communication: set an expectation for open communication among all involved. Aim to communicate in an understandable, accepted, and positive manner. The subcomponents of this step include ensuring active participation, listening carefully, conveying clear messages, providing immediate feedback, and justifying changes in the evaluation plan.

Encourage effective practices: rely on the internal procedures or systems within a collaborative evaluation. Effective practices promote methods or habits that improve the quality of the evaluation and its outcomes. This step encourages appreciation for individual differences, fairness and sincerity, benchmarking, teaching by example, flexibility, and creativity.

Follow specific guidelines: identify and adhere to the guiding principles and standards both for partner collaboration and for evaluation design, use, and assessment.

Figure 7.1. The Model for Collaborative Evaluations (MCE)



Source: "Collaborative Evaluations: Step-by-Step" Second Edition © 2012 by Liliana Rodríguez-Campos & Rigoberto Rincones-Gómez. Published by Stanford University Press (Rodriguez-Campos & Rincones-Gómez, 2012). Used with permission of the authors.

Considerations and Challenges

This evaluation approach is distinct in its flexible approach to collaboration among evaluators, clients, and partners. Collaborative evaluations acknowledge and embrace a varying degree of involvement: from the partners serving in a consultant capacity to co-leading the evaluation to partner lead evaluation. Collaborative evaluations allow for active and open communication and unification of parties in the evaluation approach and scope to ensure consistent knowledge sharing and well-defined responsibilities. A goal is to use the evaluation results. Documenting the collaborative evaluation process and key decisions made when and by whom could minimize the impact of potential biases on the evaluation.

Culturally Responsive and Equitable Evaluation (CREE)

Culturally responsive and equitable evaluation (CREE) is both a philosophical stance and methodological approach to evaluation. Rather than an evaluation method, CREE can enhance evaluation methods by promoting democracy and social justice, both within the evaluation process and as a result of it. Evaluators and partners inform CREE by intentionality, transparency, and equity. CREE acknowledges the historical legacy of structural and systemic oppression and the trauma from this legacy (Cook, 2014; Hood, Hopson, & Kirkhart, 2015; Hood, Hopson, & Frierson, 2015). CREE prioritizes community wisdom and lived experience, seeking to involve community partners in evaluative processes at a level that extends beyond the dehumanizing gestures of tokenism (Arnstein, 1969).

CREE involves being aware of and responsive to cultural nuances at the individual and community levels and in programmatic and/or organizational cultures. CREE advances equity by increasing access to participation in the evaluation process. Such participation informs strategy, program improvement, decision-making, policy formation, and change. Key components of CREE include:

- Conducting a landscape scan in partnership with cultural guides or community liaisons
- Facilitating a collaborative co-creation process, including ongoing check-ins with community members
- Partnering with community members
- Community-engaged dissemination, including community storytelling

These components prioritize a more human-centered (and thereby a less extractive) approach, distinguishing CREE-informed evaluation. In addition, CREE-informed evaluation can confirm the results, making recommendations more robust and reliable (Kirkhart, 2010).

CREE requires relationships and trust-building. This approach can require more time and other resources (including material resources to compensate community members for their expertise). However, CREE helps to ensure that evaluations are high-quality and align with the American Evaluation Association Guiding Principles (or sub-principles). These principles include Systematic Inquiry, Respect for People, and Common Good and Equity (American Evaluation Association, 2018).

Considerations and Challenges

CREE may require additional time and resources. Effective planning is essential. Ideally, evaluators will integrate CREE approaches into every stage of evaluation, from design to dissemination. Evaluation budgets often do not account for the actual cost of evaluation engagement. Consider what aspects of CREE are most essential for the evaluation to reflect the values, voice, and needs of the community. Providing data is time-consuming, and CREE requires that time and effort are not only acknowledged but also appropriately compensated. If evaluators have limited time, they can consider engaging a cultural guide. The guide is a community member with credibility in the community whom the evaluation team will train and compensate to work as part of the evaluation team.

Evaluation Methods

An evaluation can use quantitative or qualitative data and often includes both. Table 7.3 shows examples of quantitative and qualitative questions according to the evaluation stage.

Table 7.3 Types of Evaluation Questions by Evaluation Phase

EVALUATION PHASE	QUANTITATIVE QUESTIONS	QUALITATIVE QUESTIONS
Planning	What is the prevalence of the problem?	What are the values of the different partners? What are the expectations and goals of participants?
Implementation	How many individuals are participating? What are the changes in performance? How many or what resources are participants using during implementation?	How are participants experiencing the change? How does the program change the way individuals relate to or feel about each other? To what extent is the intervention culturally and contextually valid?
Outcome	Is there a change in quality of life? Is there a change in biological and health measures? Do those involved in the intervention differ from those who were not?	How has the culture changed? What themes reflect the participant's experience? What metaphors describe the change? What are the participant's personal stories? Were there any unforeseen benefits?
Reporting and Dissemination	How evaluators report program outcomes to funders, program implementers, communities, and policymakers?	What is the meaning of the evaluation findings for funders, program implementers, communities, and policymakers?

Source: Holland & Campbell, 2005; Newcomer et al., 2015; Steckler et al., 1992

Quantitative Methods

Quantitative data measure the depth and breadth of a project (e.g., the number of people who participated in or completed the program). Quantitative data collected before and after an intervention can show its outcomes and impact. The strengths of quantitative data for evaluation purposes include:

- Their generalizability (if the sample represents the population)
- Ease of analysis
- Consistency and precision (if collected reliably)

The limitations of using quantitative data for evaluation can include:

- Poor response rates from surveys
- Difficulty obtaining documents
- Difficulties in valid measurement

In addition, quantitative data do not provide an understanding of the program's context and may not be robust enough to explain complex issues or interactions (Choy, 2014; Garbarino & Holland, 2009; Holland & Campbell, 2005).

Qualitative Methods

Qualitative observations by researchers or participants may help explain behaviors, as well as social context and meanings. Researcher observations can include watching a participant or program, videotaping an intervention, or recording people asked to "think aloud" during an activity (Ericsson & Simon, 1993; Smit & Onwuegbuzie, 2018).

Interviews with individuals or groups are especially useful for exploring complex issues. Interviewers may conduct interviews under structured and controlled conditions, or they may use a loose set of open-ended questions. It may help to record interviews, with appropriate permissions, to analyze for themes or content. Some interviews have a specific focus, such as a critical incident that an individual recalls and describes in detail. Another type of interview focuses on a person's perceptions and motivations.

An experienced and trained facilitator can run focus groups. The facilitator leads a discussion among a selected group of people with specific characteristics (e.g., participated in the program undergoing evaluation). Focus group participants discuss their ideas and insights in response to open-ended questions from the facilitator. The strength of this method is that group discussion can provide ideas and stimulate memories as discussion occurs (Krueger & Casey, 2000; Massey, 2011; Morgan, 1997). Limitations of qualitative data for evaluation include lack of generalizability, the time-consuming and costly nature of data collection, and the difficulty and complexity of data analysis and interpretation (Choy, 2014; Patton, 2002).

Mixed Methods

The evaluation of community engagement initiatives may need both qualitative and quantitative methods because of the diversity of issues addressed (e.g., population, type of project, and goals). The choice of methods should fit the need for the evaluation, its timeline, and available resources (Holland & Campbell, 2005; Posavac, 2015; Steckler et al., 1992). A mixed-methods approach can contribute to transformative evaluation. Transformative evaluation prioritizes social justice by centering the voices and experience of those typically marginalized in the evaluation process. Mixed methods are integral to transformative evaluation because of the combination of inductive and deductive inquiry and collection of qualitative and quantitative data. This allows for multiple ways of knowing and communicating, promoting accessibility for participation in evaluation and a well-rounded understanding of the areas of interest. Using transformative evaluation urges evaluators to begin with qualitative data collection to learn about the community, develop trusting relationships, and work to supplement their qualitative inquiry with quantitative data sources (Mertens, 2012). A transformative mixed methods design often includes a cyclical collection of qualitative and quantitative data that inform program or policy application, evaluation, and improvement. Employing mixed methods can help ensure that transformative evaluations are inclusive and holistic.

Rapid Community Assessment (RCA)

During COVID-19, rapid community assessment (RCA) approaches to evaluation, as well as research and data collection, received increased attention (Khubchandani et al., 2021). RCA uses methods designed to quickly gather social, cultural, and behavioral information relevant to specific community problems and issues (Harris et al., 1997; Sharma et al., 2020). The CDC recently developed a model of RCA for the COVID-19 vaccine. The methods are adaptable for other issues or topics of interest (Agency for Toxic Substances and Diseases Registry, 2018; Andersen et al., 2021). The CDC suggests five steps for conducting RCA (Centers for Disease Control and Prevention, 2021):

1) **Identify objectives and community(ies) of focus**
2) **Plan for the rapid community assessment**
3) **Collect and analyze data**
4) **Report findings and identify solutions**
5) **Evaluate your efforts**

Step 1 of RCA consists of identifying the primary objectives, questions that need answers, and the population of focus (Centers for Disease Control and Prevention, 2021). Step 2 involves meeting with key community partners and others with an interest in the community to partner with for assessment (Centers for Disease Control and Prevention, 2021). Step 2 also develops the assessment team. The team should include individuals who have the background, skills, and experience needed to complete the RCA (Centers for Disease Control and Prevention, 2021). The assessment team will plan how to implement the assessment and identify the resources needed to implement the RCA (Centers for Disease Control and Prevention, 2021). Step 3 includes collecting data by employing data collection activities to identify relevant social and behavioral drivers (Centers for Disease Control and Prevention, 2021). RCA data collection can include qualitative and quantitative methods (Sharma et al., 2020). Data analysis strategies will depend on the methods used to conduct the RCA. Step 4 is to report findings and identify solutions with community partners and other key partners (Andersen et al., 2021). Step 5 is to evaluate the work to determine if there is enough information to identify solutions and develop recommendations to improve health (Centers for Disease Control and Prevention, 2021).

Considerations and Challenges

RCA is a valuable enhancement for community-engaged research or evaluation, particularly in situations where time and/or resources are scarce. RCA findings can inform effective and culturally responsive health education programs. Findings can shape the development of materials for health promotion and disease control (Centers for Disease Control and Prevention, 2022; Khubchandani et al., 2021). Researchers may use RCA findings to develop hypotheses or directions for larger, more time-intensive studies (Andersen et al., 2021).

Evaluating the Community Engagement Process

Evaluation experts may develop conceptual frameworks to understand and evaluate how community-academic partnerships function (Jagosh et al., 2015; Khodyakov et al., 2011; Lasker & Weiss, 2003; Wallerstein & Duran, 2010). Several of these frameworks propose broad areas that contribute to partnership functioning, including environmental, structural, and group dynamics; partnership programs and interventions; and measures of partnership effectiveness. The increasing interest in community-engaged approaches has highlighted the responsibility for engaged partnerships to measure and demonstrate evidence of their impacts (Luger et al., 2020; Southerland et al., 2013). Measures exist to evaluate the process of engaged research (e.g., how community engagement occurred), including:

- Examining group dynamics within the partnership
- Assessing whether the partnership aligned with CBPR goals and principles and enhanced collaboration
- Determining satisfaction with the engagement.

Measures also exist to evaluate the outcome or impact of community engagement, including:

- System and capacity changes
- Community capacity for research/evaluation
- Sustainability
- Ongoing funding
- Population health outcomes
- Policy changes

Evaluation teams should conduct both process and outcome assessments of partnerships. Partners should engage in regular assessment of their partnership to allow for any needed adjustments and to contribute to the partnership's sustainability (Caron et al., 2015). Some questions to consider when evaluating community engagement include the following (Centers for Disease Control and Prevention, 2009; Green et al., 1995; Israel et al., 1998):

- Are the right community members at the table? Ask this question throughout the program or intervention because the necessary community members might change over time.
- Does the process and structure of meetings allow for hearing all voices and valuing all input equally? For example, where do meetings take place, at what time of day or night, and who leads the meetings? What is the mechanism for decision-making or coming to consensus? How are conflicts handled?
- How are community members involved in developing the program or intervention? Do they help conceptualize the project, establish project goals, and develop or plan the project? How do community members help assure that the program or intervention is culturally sensitive?
- How are community members involved in implementing the program or intervention? Do they assist with the development of study materials or the implementation of project activities or provide space with a connection to the community?
- How are community members involved in program evaluation or data analysis? Do they help interpret or synthesize conclusions? Do they help develop or disseminate materials? Are they coauthors of all publication or products?
- What kind of learning has occurred for both the community and the academics? Have community members learned about evaluation or research methods? Have academics learned about community health issues? Are there examples of co-learning?

As detailed in Chapter 8, there are several tools and measures to guide the evaluation of community involvement in a partnership. The partners should identify or tailor existing assessment tools for their partnership. If necessary, they may need to create a new tool. An advantage of creating a tool is partners can tailor it to the program. A disadvantage is that the results may not be comparable across other programs with shared goals. Most important is that there is an investment of time in collectively deciding what is most valued and how to measure it.

Summer Fellows attending a National Center for HIV AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) internship program. *Public Health Image Library, 2012.*

Benefits and Challenges

Benefits

Assessing community-academic partnerships must be community-engaged to accomplish the partnership's goals and have accurate data. Having assessment tools to gain clarity is an effective way to build morale and buy-in. Engaging the community in developing and implementing a program evaluation can improve the quality and sustainability of the program. Those representing the prioritized community bring the opportunity to "gain" or reestablish community credibility of a program or its evaluation (Henry Akintobi et al., 2011).

The evaluation of community partnerships and community engagement can benefit from social network analysis (SNA; see Chapter 6; Franco et al., 2015; Freeman & Audia, 2006; Wasserman & Faust, 1994). SNA is useful for evaluating community partnerships and their sustainability, as well as the impact of the partnership on community engagement (Eder et al., 2018; Wasserman & Faust, 1994). SNA is also useful for understanding social networks and in planning and creating organizational structures to facilitate community engagement initiatives (see Chapter 4).

Challenges

Evaluators must overcome many challenges to ensure appropriate and effective evaluation. First, conversations leading to decisions and understanding can be difficult. Evaluators may need to set boundaries need to be set. They also need to recognize the value of community-partnered evaluation. Second, evaluators may need additional time and resources. Third, evaluation may need organizational or institutional commitment for appropriate structures and resources; individual projects may not support these (see Chapter 4). Fourth, different work styles and institutional or organizational cultures may create barriers to develop or act on results. Fifth, all people involved must understand that evaluation may identify problems that make them uncomfortable. Addressing those issues contributes to the program's improvement.

Chapter Conclusion

Program evaluation can have many forms and purposes, ranging from helping to shape a program to learning lessons from its design, implementation, or outcomes. Historically, program evaluation has increased partner engagement. Engagement in the evaluation also readies partners to implement changes for improvement. This chapter details partner engagement in evaluation approaches that prescribe specific approaches consistent with the principles of community engagement. Evaluating community-engaged partnerships needs to continue. In addition, SNA and formal models of engagement may provide useful frameworks for evaluating engagement.

Those seeking to use community-partnered evaluation must guard against assuming that 1) the community understands the formal evaluation process and that 2) formally trained evaluators understand the issues that may be barriers or facilitators. One partner can be looking for data to understand the problem, while another could be looking to solve the problem. Partners should ground evaluation in an Intersectionality framework and the pursuit of authentic diversity, equity, and inclusion.

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Appendix 7: Accessible Descriptions for Complex Graphics

Figure 7.1—The Model for Collaborative Evaluations (MCE)

Figure 7.1 shows the Model for Collaborative Evaluations or MCE, which includes

- Planning
- Executing
- Reporting

The MCE has 6 key activities:

- Identify the Situation
- Clarify the Expectations
- Establish a Collective Commitment
- Ensure Open Communication
- Encourage Effective Practices
- Follow Specific Guidelines

Each activity links to planning, evaluating, and reporting, and each activity has sub-activities.
The activities and sub-activities include

- **Identify the Situation**
    - Identify stakeholders [currently referred to as key partners to replace the word stakeholder]
    - Identify logic model elements
    - Identify potential SWOTs (strengths, opportunities, weaknesses, and opportunities)
    - Identify the evaluation scope
    - Identify critical evaluation activities
- **Clarify the Expectations**
    - Clarify the role of the evaluator
    - Clarify the role of the C Ms
    - Clarify the evaluand criteria and standards
    - Clarify the evaluation process
    - Clarify the evaluation budget
- **Establish a Collective Commitment**
    - Establish a shared evaluation vision
    - Establish recommendations for positive actions
    - Establish means toward conflict resolution
    - Establish decision-making procedures
    - Establish reward options
- **Ensure Open Communication**
    - Ensure active participation
    - Ensure careful listening
    - Ensure the message is clear
    - Ensure immediate feedback
    - Ensure the need for change is justified
- **Encourage Effective Practices**
    - Encourage appreciation for individual differences
    - Encourage fairness and sincerity
    - Encourage benchmarking
    - Encourage teaching by example
    - Encourage flexibility and creativity
- **Follow Specific Guidelines**
    - Follow guiding principles for evaluations
    - Follow evaluation standards (such as personnel, program, and student evaluation standards)
    - Follow the collaboration guiding principles

◀ *Return to Figure 7.1*

CHAPTER 8: COMMUNITY ENGAGEMENT MEASURES AND ASSESSMENT OF PRACTICES WITH POTENTIAL FOR SUCCESS

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As community engagement and community-engaged research (CEnR) have grown, practitioners increasingly need to explain how engagement works to produce desired health and health equity outcomes. Two strategies are helpful for practitioners and partners to address this need. First, they can use models that describe how groups working together can best engage with communities, as well as the essential factors for engagement. Second, they can use measures or assessment tools that provide ways to assess the extent and quality of engagement.

Why do Measures Matter?

We start with the question, "What do we choose to measure, and why?" Partnerships may have different reasons for choosing to measure or assess different constructs. They may be at an early stage, just developing trust, or have a long-standing collaboration. Or they may have come together for different reasons in the first place (e.g., to work on a single project or to commit to long-term equity change). At a program level, measurement can tell us if something is working or not. As discussed in Chapter 7, it is important to know whether a program or intervention is effective or ineffective. We also need to know whether we should continue, revise, or stop a program. Often, partnerships undertake measurement because of funding requirements. However, evaluation results can also identify the need for additional resources. With effectiveness data, an existing funder may continue to support the project and/or recruit new funders. Partnerships may want to track their own progress or engage in quality improvement. Regular collective reflection sessions enable partnerships to evaluate where they are at a particular point in time. They can identify successes and challenges or capacities they want to strengthen.

What we measure depends on our values. Chapter 1 highlights the importance of values in community engagement. Measuring partnership practices and outcomes offers choices. Most important for this chapter is the role of community members in deciding what measures to develop and use. Community members are keepers of knowledge and experts in their lived experience and perspectives. Community involvement in developing measures can thus enable greater ability to make sense of assessments for local use. For example, community members can help anchor questions and response options that distinguish symbolic from authentic engagement. This is an important distinction for understanding how engagement contributes to desired outcomes.

Before launching into what measures of engagement exist, or how community-engaged partnerships can develop their own measures, we want to present some core principles and strategies to consider.

Measure What Matters to the Community

What is valued within the community and diverse partners informs the partnership on what they decide to measure. Negotiation is important because partners may have different reasons for assessing or evaluating practices and outcomes. If a central purpose is to generate evidence for continued sustainability or funding, it may be useful to use validated measures. The partnership may also want to compare these measures to national benchmarks. If the purpose is to reflect on the partnership's progress, review of national tools may help partners choose scales of interest. It may be more important to for partnerships to start with what the community values and then obtain partner input on developing tools and measures. The partnership can track measures for baseline and ongoing assessments to help move toward desired outcomes.

Start with Defining Success and your Own Model of Pathways to Get There

There are two constructs worth noting in measurement of community-engaged research. First is the measure of the engagement between and across partnerships. Second is the project, program, or research outcomes. In this chapter, the primary focus is on the first, with considerations about how to approach measuring the second.

It is important for team members to identify what success would look like for them, one year later or many years later. For the partnership, this could be sustainability in funding, enhanced power-sharing, or greater honoring of community knowledge in research. For the community, this could be policy, program, or practice changes that affect a particular health issue or transform unequal conditions. Again, community indicators of success may differ from academic or agency staff indicators. Building a logic model with desired long-term and intermediate outcomes is a good first step to identify measures. The logic model should include strategies to attain outcomes. While indicators of success are important to negotiate among partners, starting with community priorities is essential.

Balance Universal and Local Context

While national or universal measures may have excellent properties, the question is whether they can work in a local context. Much has been written on the importance of adapting or "re-centering" tools into local languages and cultures. This could mean starting over and developing tools directly in the language of the community. Or it could mean translating, adapting, and testing existing tools. One helpful approach is to retain fidelity to the core function or practice that your partnership cares about (e.g., trust among partners). At the same time, the partnership can change the linguistic or cultural form of how you measure or assess that core function (Hawe et al., 2009). For example, your community may talk about trust differently than current measures offer. Demonstrating successful local adaptation, based on core practice and outcome constructs, may help other partnerships adapt tools to their linguistic and cultural contexts.

Use Mixed Methods to Broaden Questions

Measurement tools used by evaluators broadly fall into two categories, quantitative and qualitative. Evaluators conduct quantitative assessment using a numerical basis. They conduct qualitative assessment using a base of narratives and experiences. We use the term "assessment" to include both types of measures. Traditional forms of quantitative assessment are pre- and post-testing, surveys, scores, and ranking of items. Qualitative assessment includes data collection from interviews, focus groups, town halls, or ethnographic observation. These have grown to include image-based dynamic forms, often generated by community members.

Examples include photovoice, video-voice or digital stories, as well as other ways to capture narratives through poetry, storytelling, and song. Mixed methods enable a rich understanding of the breadth and depth of engagement. Mixed methods consider how partnering practices best contribute to outcomes in different cultures and contexts.

Recognize Different Ways of Knowing

Engagement must honor the contributions of much knowledge from community members and other partners, a recognition often referred to as epistemic justice or knowledge democracy (Hall et al., 2015). Linguistic and cultural differences among communities require listening to how community members themselves define core concepts, including healing, health, and equity. In one example, partners asked an American Indian/Alaska Native community what makes for "successful" Native youth. Responses included coping and behavioral lifestyle choices. They also included "connections to Native ancestry," "cultural knowledge," and "Native identity" (Friesen et al., 2012, p. 93). According to the community, it was necessary but not sufficient for successful Native youth to engage in school. The youth also needed to know the cultural "protocol" for engaging with an elder from their community.

We know that geographic or identity-based communities do not have only one knowledge base or set of definitions. Epistemic justice recognizes that communities use different knowledges that are also grounded in coherent worldviews.

Think Carefully about What NOT to Measure

Not all knowledge should be subject to measurement (Dutta, 2008). Some knowledge within communities is private or confidential and therefore outside the domain of academic or western knowledge. Communities with sensitive cultural or spiritual knowledge and practices, for example, may not share these with outsiders. Ultimately, partners need to recognize that some categories of knowledge should not be measured. Partners should play a role in decision-making about what to measure and what not to measure.

Pay Attention to Existing Measures of Practices with Potential for Success

Community engagement practitioners have identified potential best engagement practices associated with a range of outcomes. These include validated instruments co-created with community partners. While the partnership created some tools for specific research projects, many are adaptable for any community engagement initiative. They are excellent starting places for deciding what constructs partners want to measure and what existing questions and scales to use.

Some of the most robust and tested process/practice measures include:

- Trust
- Community engagement in all research stages
- Structural governance practices, such as resource sharing and formal agreements Power-sharing

Newer measures of collective empowerment include:

- Shared CBPR principles
- Projects that fit community knowledge and history
- People perceiving that they have influence or power in the partnership
- Collective reflection or evaluation of the partnership
- The partnership's ability to address equity

Internal partnership outcome measures are also available, such as skill development, or enhanced capacity of participating organizations to engage with data. Community-level outcome measures range from health risks and socio-economic determinants to protective factors of culture and social support.

Confront Power Inequities

Societal conditions of hierarchy and power are unequal, which also shapes how diverse partners collaborate. Within research, academics have power in that they are seen as experts or knowledge holders. Within clinical settings, agency staff members and practitioners may have more power than family members. Universities have the power of greater access to National Institutes of Health and other funding. This provides them with decision-making authority to facilitate or create barriers to providing funds to community organizations or members. These challenges require ethical community engagement to seek co-governance in resources and decision-making, including agreements of who owns and can use data. Measures of power inequalities need to be bidirectional. For institutions to expect trust with their communities, they have to become trustworthy. Assessing institutions' financial and administrative barriers to transforming their practices and policies is key to authentic engagement (Carter-Edwards et al., 2021). The two case studies below describe power-sharing and equal relationships. Chapter 7 also describes the importance of transforming practices and policies in the discussion of transformational participatory evaluation.

Co-Interpret Data with Community Partners for Meaning-Making

Making sense of the data or "meaning-making," through co-interpretation and reflexive practice with partners, may matter most in advocating for change. Annual partnership surveys or focus groups can inform collective reflection sessions on what partnerships are doing well and how they can strengthen their collaborative work. Having the opportunity to learn about different local practices and reflections, as well as cross-cutting case studies, can generate new understanding to help strengthen engagement practices. For community data, such as assessment of health issues or program impacts, community members provide essential expertise in interpretation, dissemination, and use of data for policy and program purposes. This becomes more important when addressing potential stigmatizing issues, such as substance abuse or other risky behaviors. The partnership should always question how they will be present and use the data in a way that is meaningful and helpful to the community without causing more harm.

Adopt Data Ownership and Sharing Agreements

Researchers are paying more attention to the ethical issues of who owns and uses data. Tribes and tribal entities have led the way in identifying community benefit conditions within their IRBs. Community ethics boards are slowly adopting these principles. Formal agreements, especially with community data, are helpful to enhance trust and shared power. Agreements have increasingly included requirements for co-authorship with community partners on articles and other dissemination products and shared or community ownership of data for future use (Rodriguez Espinosa & Richmond, 2017).

In sum, these principles and strategies support the role of community members in the decisions of what to measure, how to interpret measurements, and how to assure the responsible use of data. By reflecting community perspectives, partnerships focus on ideas that have local meaning. They integrate community knowledge in creating and answering questions. Community knowledge also influences and engagement and research designs. Partnerships ultimately lead to interpretation of data for actions that promote community stewardship and benefit.

How to Start Choosing Measures?

Identifying practice and outcome measures and assessments for a community-engaged partnership is not simple. Building from community priorities and what members of the partnership value is key. As mentioned above, there are measures that can be helpful. This chapter focuses on measures of engagement practice and outcomes. However, we include a few key systems that contain community and population-level health and social indicators for both risk factors and assets that lead to health and well-being. Aguilar-Gaxiola et al. (2014) identified a taxonomy of indicators that begins with determinants of health, then moves to categories of community health and finally to specific quantifiable measures. Another broad taxonomy is the Omaha System, a problem classification scheme (Topaz et al., 2014). For community-level indicators of health, core systems include:

- The PhenX Toolkit of Social Determinants of Health, launched by the National Institute of Minority Health and Health Disparities in 2018 (RTI International, 2022)
- The newer concept of Vital Conditions, those conditions which enable a community to thrive (Community Commons, n.d.)
- The Community Health and Land Reuse Scorecard Toolkit with community-derived indicators from 45 projects from the Agency for Toxic Substances and Diseases Registry (Agency for Toxic Substances and Disease Registry, 2019)
- Consumer-generated data that focuses on resilience as an addition to a collection of SDOH (Monsen, Austin, Goparaju, et al., 2021; Monsen, Austin, Jones, et al., 2021)

Many new engagement community indicators and measures have appeared in the past decade since the previous edition of this book. We offer here a way to categorize partnership and engagement measures: by context, mechanism, and outcomes (C-M-O; Pawson & Tilley, 1997). Context refers to the conditions of engagement for community partners or community-academic partnerships (e.g., community history of organizing and historical collaboration). Mechanism is the means by which diverse individuals interact and complete their work (e.g., group dynamics and partnering practices). Outcomes are results of the community-engagement mechanism (e.g., empowerment or sustainability of projects leading to improved health).

C-M-O can help create strategies for change, pathways, or theories of how and why community involvement facilitates change toward equity outcomes. Models or frameworks are useful for choosing measures in each category. Differences in local contexts (e.g., linguistic, cultural, or socio-economic) may shape different practices and pathways and therefore different outcomes. The core question becomes, “Under what conditions do which partnering practices or mechanisms best contribute to desired outcomes?” This question is key to understanding why particular changes happen or the meaning that people ascribe to these changes. For all community engagement, partnerships need to choose measures that focus on both the how of engagement dynamics and the what of change or outcomes.

Why do Models Matter for Driving Change?

Strong conceptual models, using C-M-O, can guide the selection of scales and tools. The purpose is to identify pathways or theories that contribute to desired partnership, empowerment, policies, and outcomes. Several models incorporate the ethics of promoting equity and social justice. In this chapter, we present two specific CBPR models as case studies to illustrate the development of measures. These are the CBPR Conceptual Model (Wallerstein & Duran, 2010) and the Measurement Approaches to Partnership Success (MAPS) model (Israel et al., 2020).

The CBPR Conceptual Model, developed and refined since 2008, has codified a systematic approach to thinking about community engagement partnering and measures in each category. The CBPR Conceptual

Model has four domains that use the C-M-O framework (Figure 8.1). Contexts (local, regional, national, and global) provide grounding for mechanisms. Mechanisms includes two areas: partnership processes and intervention/research actions. Partnership processes include relational aspects (e.g., trust, respect, conflict management), as well as structural components (e.g., the diversity of partners participating, the sharing of resources and community approval processes). These mechanisms then shape decisions made in intervention/research actions. Ultimately, these actions contribute to intermediate partnership, policy, or system changes, leading to longer-term health and social justice outcomes.

Figure 8.1 CBPR Conceptual Model Four Domains

Schulz et al. (2003) built the MAPS Model from an earlier conceptualization of partnerships. MAPS contains elements of environment and group dynamics but focuses on multiple outcomes of successful long-standing CBPR partnerships. Other models are also helpful, with a notable CTSA model that calls for bidirectional outcomes of engagement, including changes within academic institutions as well as within community settings and health (Eder et al., 2013). The Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies from the National Academies (Aguilar-Gaxiola et al., 2022) developed an important new model presented in Chapter 1. This model, A Conceptual Model to Advance Health Equity through Transformed Systems for Health, provides constructs of core community engagement principles, such as trust and shared governance. The model focuses on four outcome domains:

- Strengthened partnerships and alliances
- Expanded knowledge
- Improved health and health care programs and policies
- Thriving communities

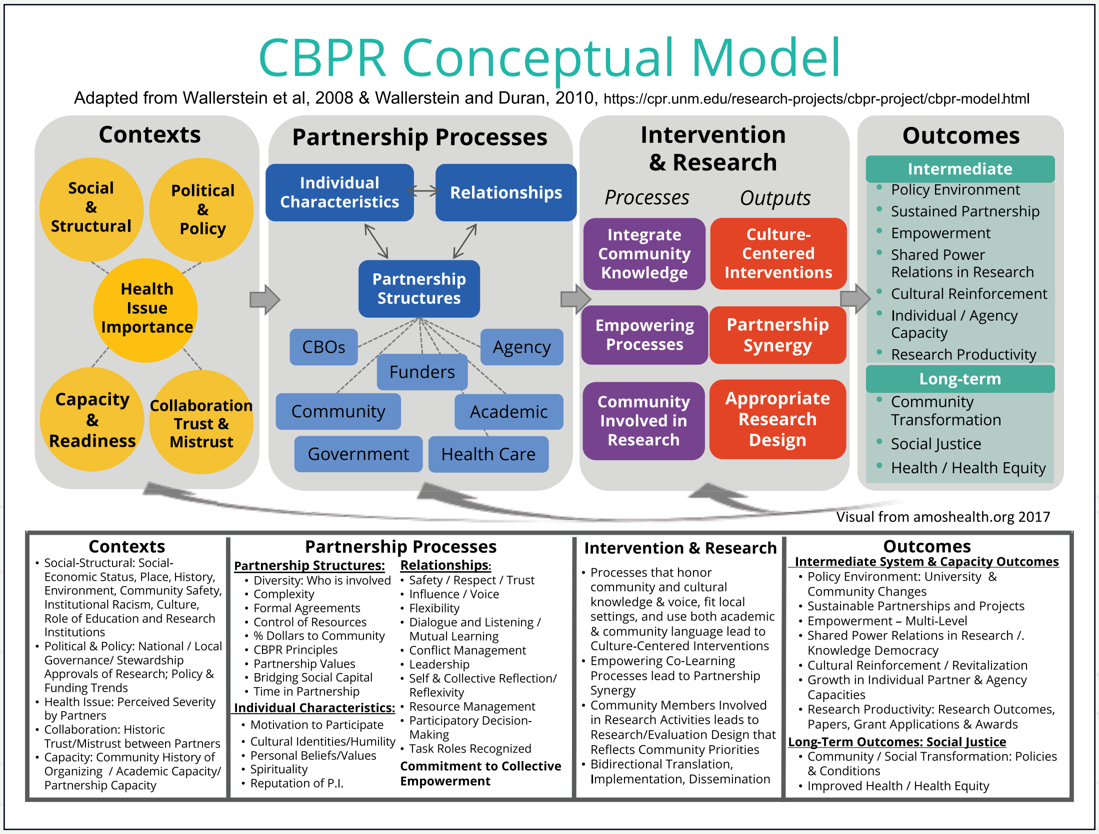
The model frames the outcomes in terms of related issues.

Case Studies in Developing Measures and Identifying Promising Practices

Engage for Equity Case Study

Since 2006 the CBPR Conceptual Model and measurement of its key practices continues to develop. In the first pilot stage (2006–2009), the University of New Mexico Center for Participatory Research, in collaboration with a national think tank of community and academic CBPR experts, conducted literature searches, drew from a previous model (Schulz et al., 2003), and used expert and community consultations to develop the CBPR Conceptual Model (Figure 8.2; Belone et al., 2016).

Figure 8.2 CBPR Conceptual Model



Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010, https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html

Visual from amoshealth.org 2017

Contexts	Partnership Processes		Intervention & Research	Outcomes
• Social-Structural: Social-Economic Status, Place, History, Environment, Community Safety, Institutional Racism, Culture, Role of Education and Research Institutions • Political & Policy: National / Local Governance/ Stewardship Approvals of Research; Policy & Funding Trends • Health Issue: Perceived Severity by Partners • Collaboration: Historic Trust/Mistrust between Partners • Capacity: Community History of Organizing / Academic Capacity/ Partnership Capacity	**Partnership Structures:** • Diversity: Who is involved • Complexity • Formal Agreements • Control of Resources • % Dollars to Community • CBPR Principles • Partnership Values • Bridging Social Capital • Time in Partnership **Individual Characteristics:** • Motivation to Participate • Cultural Identities/Humility • Personal Beliefs/Values • Spirituality • Reputation of P.I.	**Relationships:** • Safety / Respect / Trust • Influence / Voice • Flexibility • Dialogue and Listening / Mutual Learning • Conflict Management • Leadership • Self & Collective Reflection/ Reflexivity • Resource Management • Participatory Decision-Making • Task Roles Recognized **Commitment to Collective Empowerment**	• Processes that honor community and cultural knowledge & voice, fit local settings, and use both academic & community language lead to Culture-Centered Interventions • Empowering Co-Learning Processes lead to Partnership Synergy • Community Members Involved in Research Activities leads to Research/Evaluation Design that Reflects Community Priorities • Bidirectional Translation, Implementation, Dissemination	**Intermediate System & Capacity Outcomes** • Policy Environment: University & Community Changes • Sustainable Partnerships and Projects • Empowerment – Multi-Level • Shared Power Relations in Research /. Knowledge Democracy • Cultural Reinforcement / Revitalization • Growth in Individual Partner & Agency Capacities • Research Productivity: Research Outcomes, Papers, Grant Applications & Awards **Long-Term Outcomes: Social Justice** • Community / Social Transformation: Policies & Conditions • Improved Health / Health Equity

https://engageforequity.org/cbpr-model/full-model/

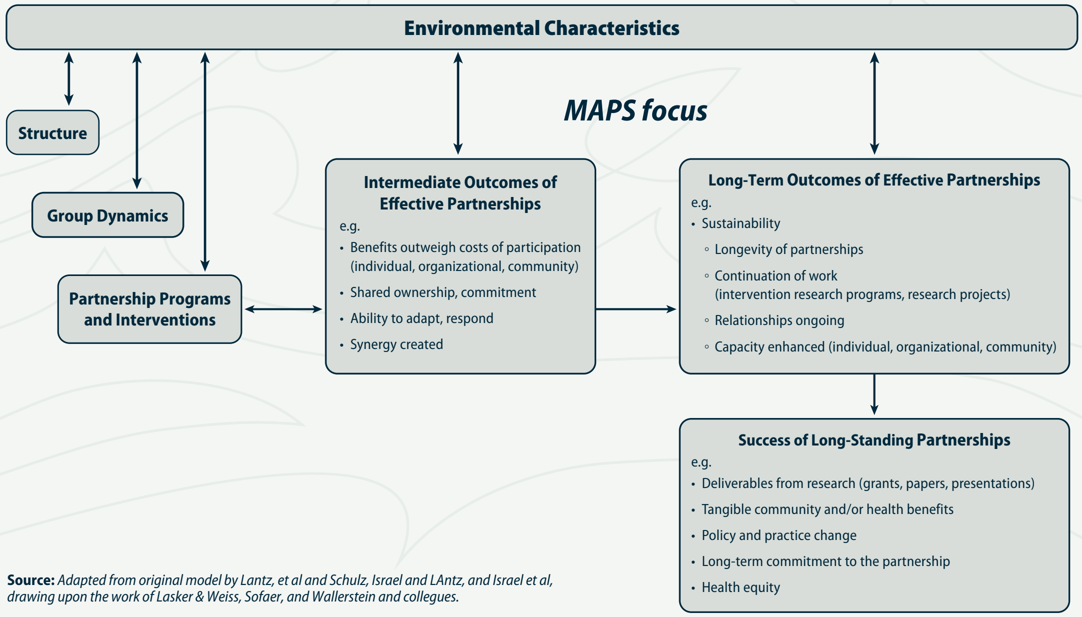
Engage for Equity has developed qualitative tools to assess and engage partnerships in collective reflection and planning through dialogue (Parker et al., 2020; see Engage for Equity, 2022). First, the River of Life exercise guides discussion about the history of the partnership, its community context, and potential next steps (Wallerstein et al., 2020). Second, partnership data reports provide survey data back to the partners to support their reflection on their strengths and areas for improvement. If desired, they can compare their data to national guides. Third, practitioners in the United States and other countries use the CBPR Conceptual Model as a planning, evaluation, and vision tool (Wallerstein et al., 2021). While the CBPR Model seems linear, it has use dynamically as an implementation framework with feedback loops (Sánchez et al., 2021). It also has use as a vision/planning or evaluation framework (see examples in Wallerstein et al., 2021) and as a training framework (Nunes et al., 2022).

In 2020, the University of New Mexico (UNM) Center for Participatory Research embarked on two new projects. The first was to create and test a condensed pragmatic and action-focused survey for multiple forms of collaborations. The PHIRE survey (Partnering for Health Improvement and Research Equity) is a 10-minute pragmatic tool. This survey builds from the practices of Engage for Equity's Community Engagement Survey and includes a few questions from the Key Informant Survey (PHIRE 2022–2024). PHIRE offers broad strokes of partner structural and relational practices that matter, benefits of partnering, and future desired outcomes. The second opportunity is a cross-cutting exploration of three academic institutional contexts (policies, climate, and practices) that may promote or inhibit sustained equity-based community engagement (Carter-Edwards et al., 2021; Eder et al., 2021; Michener et al., 2012). A new institutional assessment tool is being pilot tested. This tool includes intervention strategies that adapt the use of Engage for Equity tools, emphasizing collective empowerment and reflection for institutional change (Sanchez-Youngman et al, 2023).

MAPS Case Study

The MAPS study (launched in 2016), led by the Detroit Community-Academic Urban Research Center (Detroit URC), is a CBPR partnership established in 1995. MAPS aims to develop and validate an instrument for CBPR partnerships to evaluate their efforts toward success, as well as intermediate and long-term outcomes that contribute to success (Figure 8.3; The Detroit Community-Academic Urban Research Center, n.d.). The Detroit URC involves a decision-making board comprised of representatives from Detroit community-based organizations, the local health department, an integrated health care system, and academic researchers from the University of Michigan (Israel et al., 2001). The MAPS partnership established a sixteen-member Expert Panel of eight academic and eight community members. The panelists are actively involved in long-standing CBPR partnerships that have been operating for 6 years or longer.

Figure 8.3 Measurement Approaches to Partnership Success (MAPS) Overview



Source: *Adapted from original model by Lantz, et al and Schulz, Israel and LAntz, and Israel et al, drawing upon the work of Lasker & Weiss, Sofaer, and Wallerstein and collegues.*

MAPS provides opportunities to enhance partnership evaluation efforts. MAPS makes partnership a dimension for assessment, in addition to intermediate and long-term outcomes. The study team has developed a feedback mechanism in two phases for CBPR partnerships who have used the instrument (i.e., study participants) to share and interpret evaluation findings and to improve partnership success.

What are Some Core Engagement Practices to Measure?

We now focus on a few specific constructs that have emerged as critical to the field of community engagement.

Trust/Trustworthiness

Community engagement practitioners identify trust as a key attribute of community engagement. They recognize that trust is often assessed as a binary construct, which obscures trust's multidimensionality. An early trust assessment strategy to support Prevention Research Centers recommended surveying community, academic, and health department partners for bidirectional sharing and interpretation of the data. Partners began by describing positive trust behaviors. Then, they described behaviors that they imagined could further trust within the partnership. Lucero et al., challenged the binary conceptualization and assessment of trust by advancing a trust typology. This typology includes a range of trust: no trust, functional, proxy, and critical reflective trust (Lucero et al., 2018, 2020).

While the hope is that community engagement builds community trust, historic research injustices (e.g., the Tuskegee Syphilis Study) did not build trust. They violated ethics; lacked consent processes, including the Havasupai genetic research studies; or failed to share results in ways that were meaningful for communities. As community engagement develops, community members have assumed new research roles and responsibilities. For example, a community member may act as a researcher and research team member, consultant, advisor, community advisory board and committee member. Recent public confrontations over structural racism and systemic inequalities have contributed to the realization that community trust depends on researchers and their institutions demonstrating that they are deserving of the community's trust. Trustworthiness of institutions has become an expectation that community-academic research partnerships will be inclusive and mutually respectful (Eder et al., 2021).

The recognition that community members, patients, researchers, and academic institutions may have different experiences with trust and trustworthiness offers opportunities to develop new theories of change for engagement. Jagosh et al. (2015) identified trust and synergy as critical to supporting successful functioning of CBPR partnerships. Synergy has been well-studied as a community engagement construct that improves the likelihood of future collaborative work. This is evidenced by partnerships that sustain themselves across funding gaps (Jagosh et al., 2015).

Studying trust can help identify patterns across time or between partnerships. Studies of distinct academic institution trustworthiness may identify differences in how partners experience and interpret institutional behaviors and practices. A study of the interaction among partnerships and their institutions may help understand how to develop and sustain trust and trustworthiness.

Community Participation in All Research Stages

Colleagues at the University of California, Los Angeles, RAND Corporation, and Healthy African American Families (among others) developed measures to assess the added value of participation in mental health services research (Khodyakov et al., 2011, 2013; Ngo et al., 2016). They developed a key Community Engagement in Research Index (CERI). CERI asks questions about the level of community involvement in all stages of research. The states of research include, for example, identifying health issues, designing interview/survey questions, implementing the intervention, and analyzing, interpreting, and disseminating findings. The research collaboration incorporated three levels of engagement in the assessment:

1= ***Community partners did not participate in this activity***
2= ***Community partners consulted on this activity***
3= ***Community partners engaged actively in the activity***

The long-term Engage for Equity study further developed the CERI by creating subscales of research participation (Oetzel, Zhou et al., 2015). They also added new action items, including community use of data for community benefit and dissemination (Boursaw et al., 2021). The revised measure, Community Engagement in Research Actions (CERA) includes three subscales:

1) **Background and design**
2) **Analysis and dissemination, such as giving presentations at conferences**
3) **Community action, such as informing relevant policymakers about data and producing useful findings for community action**

While these stages and questions focused on collection and use of data, they are adaptable to any collaboration or community engagement.

Structural Governance

Working from a value of community stewardship seeks to assure that any research or engagement project follows authentic participatory principles and commitments made to the community (Oetzel, Villegas, et al., 2015). Structural governance, or the ways in which partners make decisions and take action, is key to ensuring community stewardship (Sanchez-Youngman et al., 2021). A new measure of structural governance is validated with four subscales:

1) **Approval on behalf of the community, such as tribal IRBs**
2) **Community-based advisors, such as a community advisory board**
3) **Joint decision-making between academic and community partners**
4) **Resource sharing, or the distribution of funds to community entities.**

Historically, tribal nations have had meaningful authority over partnered projects on their lands. Other communities are increasingly embracing similar governance. They include community IRBs, ethics boards, or even community councils who assume greater decision-making beyond a traditional community advisory board role.

Shared Power

Power-sharing has been a key construct in community engagement. Power-sharing occurs in practices of engagement (i.e., joint decision-making, as indicated in structural governance). Power-sharing also occurs through outcomes of engagement (i.e., perceived shared power in research, enhanced structural governance, community engagement in research dissemination, or producing findings grounded in community benefit (Wallerstein et al., 2019).

Collective Empowerment

Collective empowerment in community-engaged research emphasizes equality and action through a partnered approach. Using empowerment measures from community psychology, collective empowerment links context and community engagement processes to outcomes. The Engage for Equity study developed a measure of commitment to collective empowerment that includes four scales (Boursaw et al., 2021):

1) **Partnering principles (e.g., the project builds from community strengths)**
2) **Community fit (the project is responsive to community histories and culture)**
3) **Influence (people perceive they have power in the partnership)**
4) **Collective reflection (partners have regular evaluations and reflections on power and privilege)**

Other Constructs and Modalities of Assessment

Over the last several decades, many established CBPR centers have developed their own qualitative and quantitative methods and instruments. Once such center is the long-standing Detroit Community-Academic Urban Research Center, which conducted the MAPS study (Israel et al., 2013). The network of CTSA awardees since 2006 has supported growth of community engagement across academic health centers, with different institutions developing measures and assessment tools. The University of Kansas Community Tool Box (Center for Community Health and Development at the University of Kansas, 2022) has provided innovative tracking tools to enable communities and coalitions to conduct self-evaluations (Fawcett et al., 2017). Green et al. first published in 1995 (and later amended) their reliability-tested guidelines for funders, evaluators, and partnerships to assess the extent to which projects were using participatory criteria at all stages of the research process (Green et al., 1995; Mercer et al., 2008). One of the earliest and still extensively used instruments is the Wilder Collaboration Factors Inventory (Mattessich et al., 2001). Open-ended focus group and interview guides for in-depth community engagement case studies are also available at the UNM Center for Participatory Research (UNM Health Sciences Center, Center for Participatory Research, n.d.) and (Engage for Equity, 2022). The National Cancer Institute developed an interactive Grid-Enabled Measures (GEM) website (National Cancer Institute, 2022). GEM includes behavioral, social science, and other relevant scientific constructs for dissemination and implementation, community collaboration, CBPR, and CEnR, which complements their team science toolkit (National Cancer Institute, 2021). While separate, measures from the Consolidated Framework for Implementation Research may also be useful (see Lewis et al., 2015).

Finally, for community equity measures, we return to the taxonomies of SDOH and others identified in this chapter. Practitioners have growing critical understanding of structural racism and other intersectional inequities by class, gender identity, sexual orientation, disability, immigrant/refugee status, etc. They and their partners incorporate this understanding in developing and testing measures at socio-political, cultural, and institutional levels (Ford et al., 2019). As with all measures and assessments, this chapter calls for community-engaged initiatives to use the data for actionable change in policies and conditions. This is particularly relevant for confronting long-standing histories of racism, historical trauma, and other intersectional abuses.

Most recently, the National Academy of Medicine, working with the Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies developed a Conceptual Model to Advance Health Equity through Transformed Systems for Health (Aguilar-Gaxiola et al., 2022). Chapter 1 introduces this model. The model incorporates four domains of measurable outcomes:

- Strengthened partnerships and alliances
- Expanded knowledge
- Improved health and health care programs and policies
- Thriving communities

Other literature from community psychology and health education has contributed measures in community capacity (Liberato et al., 2011) and empowerment at three levels: psychological, organizational, and community (Douglas et al., 2016; Rappaport, 1987; Wallerstein & Duran, 2006; Zimmerman, 2000). Empowerment measures have been most extensive for psychological empowerment (Speer et al., 2019). In a systematic review, Cyril et al. (2016) identified 17 studies with empowerment measured at an individual level, with two studies of community and one study of organizational empowerment. Further, only 45% of the studies had sufficient evidence of psychometric (the study of measurement) validity and reliability. Organizational measurement has focused on health promotion programming (Laverack & Wallerstein, 2001). A review for the WHO found empowerment indicators at the national or regional level (Laverack & Pratley, 2018).

Popay et al. identified qualitative markers for tracking increases in community collective control (Ponsford et al., 2020; Popay et al., 2020). They used an emancipatory framework of power (power with, power within, and power to) with communities seeking to confront the structural forces that produce inequities.

The MAPS model focuses on outcomes of success for long-term partnerships. The model emphasizes sustainability and concrete research outcomes, policy changes, and tangible community benefits (Israel et al., 2020). The CTSA adds recognition of the importance of academic institutional changes as needed outcomes, not just a focus on communities (Eder et al., 2021). The CBPR Conceptual Model, while created for research, is gaining traction in its use for many types of engagement (Wallerstein et al., 2021). It offers the value of a C-M-O framework that enables the study of contexts that influence pathways of change (both structural and relational) leading to outcomes.

What is our Call to Action?

Evaluations of community engagement and community-engaged/CBPR research benefit from models, measures, and theories of change that follow the C-M-O framework. Previous evaluation tools were often developed locally and lacked psychometric validation because sample sizes were small. More recent tools incorporate large samples of partnerships and have strong measurement validity and reliability. Recent tools have moved beyond a focus on group dynamic and relational pathways. Tools include structural pathways, such as community approval mechanisms and other forms of power-sharing and co-governance. Tools now include many outcomes, i.e., partnership outputs. Outcomes include culture-centered interventions; intermediate outcomes in capacities, policy changes, and partnership sustainability; and community outcomes that can improve health and health equity.

With these new emphases, the possibility of theorizing and learning from local and national cross-site studies has grown. As demonstrated with the Engage for Equity and MAPS case studies and identification of specific core constructs, assessments of partnering practices and outcomes can build theories of change. For example, documenting the historical context of research mistrust has shaped a larger focus on structural mechanisms of co-governance. Together with relational strategies that build trust, theories of change help shape outcomes that lead to greater equality. Some theories and outcomes may be generalizable, such as the role of collective empowerment (Oetzel et al., 2022) or the benefit of a strong community partner organization for successful advocacy for policy change (Minkler et al., 2012). In addition, community capacity supports power-sharing (Ward, 2020). Other theories of change may not be generalizable but are equally valuable as contextualized knowledge from local partnerships and communities.

In summary, it is most important to recognize that engagement processes are dynamic and ever-changing. Partnerships need to identify what practices are most valuable for them to assess and strengthen as they work toward their own outcomes and goals. There is a need for assessments and measures that support actions to strengthen community self-determination, respect, and sustainability of engagement. At the same time, assessments and measures must confront the structural inequities of racism and other unjust systems of oppression. This demands flexibility for listening to what the community and partnerships most value and for participating in advocacy, policy, and other actions that promote health, social, and racial equality for all.

A rodeo caller at a community event. *ATSDR, 2022.*

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Students and environmental health professionals assessing sites in a community with several blighted properties. *ATSDR, 2022.*

Example: Deepening Multidirectional Cultural Understanding Among Tribal Community Members and Research Scientists

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Background and Purpose

The University of New Mexico Center for Native American Environmental Health Equity Research (Native EH Equity Center) is a Center of Excellence on Environmental Health Disparities. The foundation of our center is long-standing partnerships between researchers at multiple academic institutions and communities on three tribal nations with distinct cultures, languages, and traditions. Our research team focuses on environmental metals found in abandoned mines and mine waste in tribal communities (Blake et al., 2015). We assess potential impacts of metal contamination in tribal health and exposure disparities. A key interest of our team is how cultural and traditional practices influence exposure and health (Lewis et al., 2017).

The Native EH Equity Center's Community Engagement and Dissemination Core (CEDC) mission is to increase community environmental health research capacity. We work with researchers and community leadership and members to create sustainable, culturally informed materials and strategies that support our mission. Our goal is to achieve tribal environmental health equity. To reach this goal, we partner with communities to conduct environmental health research that integrates traditional ecological knowledge and culturally appropriate designs, data collection methods, and interpretation of.

Methods

In October 2018, the Native EH Equity Center CEDC organized a poster session at the 10th International Conference on Metal Toxicity and Carcinogenesis in Albuquerque, New Mexico. While traditionally focused on bench science, the conference holds integrated sessions on metals and population studies. The conference included a plenary talk by a Native EH Equity Center member. We used a community engagement process that prepared both researchers and community members for this joint poster session. The CEDC team worked with the planning committee to:

1) **Design an integrated session for community posters,**
2) **Work with researchers to develop lay versions of their poster abstracts, and**
3) **Work with community members to develop posters that conveyed their exposure and health concerns using their language and world views**
4) **Work with the community to make recommendations for future work.**

Our approach helped partnership-building be multidirectional by immersing partners in each other's cultures to deepen understanding that enhanced working and personal relationships. We submitted abstracts to the conference organizers for review for the poster session presentation. After that, researchers held several work sessions with community members to develop their posters. Community members contributed archival photos, historic documents, storytelling, and oral histories to craft each poster. They collaborated with Native EH Equity Center researchers to refine the text of the posters and participated in poster presentation practice sessions.

Results/Outcomes

During the conference, our team of researchers and community members presented 26 posters. These included community voices, community engagement, pilot projects, and biomedical and environmental research projects. Community members from Navajo Nation, representatives of community organizations on the Cheyenne River Sioux Tribe, and the Crow Environmental Health Steering Committee presented posters. A partner from the Cheyenne River Sioux Tribe also delivered a platform presentation at the conference. They described the risk assessment process that the tribe is negotiating with the U.S. Environmental Protection Agency (EPA, Region 8) to evaluate gold mine tailing releases from the Homestake Mining Company of California, Inc. The risk assessment is focusing on potential impacts of arsenic contamination in the floodplains of the Cheyenne River.

Following the conference, the presenters displayed their posters in the community. They also used their posters to inform chapter government policy regarding abandoned uranium mines and land-use planning issues. Another community used its poster to give oral comments on what it considered to be an absence of tribal cultural knowledge to inform a federal plan for remediating local abandoned uranium mines.

Implications for Advancing Health Equity

Preparing for the conference helped our collaboration of scientists and community members build and achieve tribal environmental health equity. The support from the research team and conference organizers paired well with the number of community participants and informal atmosphere of the small conference. As a result, we benefitted from a unique opportunity for our partnership. Community members experienced how scientists interact with each other, and scientists deepened their understanding of traditional ecological knowledge and culture. Community members participated in one-on-one discussions with scientists from around the world. The community members and scientists contributed meaningfully from our experiences. Overall, we expanded awareness of how scientists and community can collaborate around research to address community needs. The collaboration also helped community members gain an appreciation for the range of methods used in understanding the relationship between exposures and health. Collectively, these experiences strengthened our partnerships through the Native EH Equity Center and led to deeper understanding of issues for both the scientific research team and community partners.

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Appendix 8: Accessible Descriptions for Complex Graphics

Figure 8.2—CBPR Conceptual Model

Website: https://engageforequity.org/cbpr-model/full-model/

Figure 8.2 is a chart that describes the full C B P R Conceptual Model based on

- Contexts
- Partnership Processes
- Intervention and Research
- Outcomes

Contexts are:

Social and structural, including social-economic status, place, history, environment, community safety, institutional racism, culture, role of education, and research institutions

Partnership Processes include

- Partnership Structures:
  - Diversity: Who is involved
  - Complexity
  - Formal agreements
  - Control of resources
  - Percent of dollars to community
  - CBPR principles
  - Partnership values
  - Bridging social capital
  - Time in partnership

Individual Characteristics include

- Motivation to participate
- Cultura identities/humility
- Personal beliefs/values
- Spirituality
- Reputation of principal investigator, or P I

Relationships include

- Safety/respect/trust
- Influence/voice
- Flexibility
- Dialogue and listening/mutual learning
- Conflict management
- Leadership
- Self and collective reflection/reflexivity
- Resource management
- Participatory decision-making
- Task roles recognized

The partnership structures inform a commitment to collective empowerment.

Outcomes include intermediate and long-term outcomes.

Intermediate System and Capacity Outcomes include

- Policy environment: University and community challenges
- Sustainable partnerships and projects
- Empowerment—multi-level
- Share power relations in research/knowledge democracy
- Cultural reinforcement/revitalization
- Growth in individual partner and agency capacities
- Research productivity: Research outcomes, papers, grant applications and awards

Long-term Outcomes: Social Justice including

- Community/social transformation: Policies and conditions
- Improved health/ health equity

◀ *Return to Figure 8.2*

Figure 8.3—Vaccine Infographics

Figure 8.3 outlines the MAPS focus in a chart.

At the top of the chart is "*Environmental Characteristics*."

Environmental Characteristics connects with:

- Structure, Group Dynamics, and Partnership Programs and Interventions
- Partnership Programs and Interventions
- Intermediate Outcomes of Effective Health Partnerships
- Long-term Outcomes of Effective Partnerships

Also, there are connections between Partnership Programs and Interventions, Intermediate Outcomes of Effective Partnerships, and Long-term Outcomes of Effective Partnerships. The long-term outcomes connect with Success of Long-Standing Partnerships

Examples of Intermediate Outcomes of Effective Partnerships include

- Benefits outweigh costs of participation (individual, organizational, community)
- Shared ownership, commitment
- Ability to adapt, respond
- Synergy created

Examples of Long-term Outcomes of Effective Partnerships include

- Sustainability
- Longevity of partnerships
- Continuation of work (intervention research programs, research projects)
- Relationships ongoing
- Capacity enhanced (individual, organizational, community)

Examples of Success of long-standing Partnership include

- Deliverables from research (grants, papers, presentations)
- Tangible community and/or health benefits
- Policy and practice change
- Long-term commitment to the partnership
- Health equity

◀ *Return to Figure 8.3*

CHAPTER 9: COMMUNITY ENGAGEMENT TO PROMOTE HEALTH EQUITY THROUGH IMPLEMENTATION SCIENCE

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There is growing evidence that community engagement is central to successful and widespread adoption, implementation, sustainability, and scale-up of effective interventions, programs, practices, and policies (i.e., "evidence-based interventions" [EBIs]). In this chapter, we focus on how community engagement and inclusion is key to improving health equity from intervention planning, development, evaluation, dissemination, and implementation to sustainability. Implementation science (IS) efforts need to center the voices of community members and practitioners. This helps to build trust and ensure early and ongoing engagement by partnering and co-creating solutions to address inequities. Such partnerships are needed for wide adoption and sustainability of potentially successful programs for improving health. This is particularly significant among communities that have been historically and systematically marginalized, who could most benefit from partnerships. In the following sections, we describe core pillars of community engagement to promote health equity in the context of IS. We also provide examples to demonstrate the use of community engagement in implementation efforts.

Community Engagement in the Context of Implementation Science

Community engagement is important for spotlighting community priorities and creating and sustaining changes and infrastructure needed to promote health equality (Wallerstein & Duran, 2010). The field of IS has focused on reducing the well-documented gap between research (e.g., EBIs) and practice (e.g., in clinical, community, and public health settings). It can take 15–17 years to integrate a modest amount of research into practice (Balas & Boren, 2000; Khan et al., 2021; King & Baumann, 2017). Disseminating EBIs is important for reducing the gap between research and practice (Brownson et al., 2013). In the science of implementation, we focus on strategies to promote adoption and use of EBIs (National Institutes of Health, 2021).

A community meeting. *Public Health Image Library, 2009.*

Community engagement is essential to increasing the uptake of EBIs in clinical, community, and public health settings. These settings include churches, worksites, community-based organizations, clinics, departments of public health, schools, and other organizations. Partnerships that value and include diverse expertise also improve the acceptability, appropriateness, practicability, and delivery of EBIs.

Potential community partners in IS efforts include the individuals and populations that are the intended audience for the EBI, as well as practitioners involved in the delivery of the EBIs. The intended audience may include:

- Physicians
- Counselors
- Social workers
- Community health workers
- Nurses
- Educators
- Those making decisions about interventions, including policymakers, organizational leadership, pastors, school principals, and administrators

In this chapter, we note opportunities for research and community partners to collaborate on efforts to implement EBIs to promote health equity. We also summarize and define the key terms commonly used in implementation science.

Table 9.1 Key Terms in Implementation Science and Their Definitions

CONSTRUCT	DEFINITION
Implementation research	Study of strategies that promote the adoption and integration of EBIs into routine clinical, community, and public health settings (National Institutes of Health, 2021).
Dissemination research	The active approach of spreading evidence-based information to target audiences using planned strategies (Brownson et al., 2013).
Evidence-based interventions	"Programs, practices, principles, procedures, products, pills, and policies" that are effective at improving health behaviors, health outcomes, or health-related environments (Brown, 2017).
Implementation strategies	"Methods or techniques used to enhance the adoption, implementation, and sustainability" of EBIs (Powell et al., 2015; Proctor et al., 2013).
Adoption	Intention, initial decision, or action to try or employ an EBI (Proctor et al., 2011).
Sustainability	After a defined period of time, the continued delivery of a program, clinical intervention, and/or implementation strategies and/or maintenance of individual behavior change (i.e., clinician, patient)/ The program and individual behavior change may evolve or adapt while continuing to produce benefits for individuals/systems" (Moore et al., 2017).
Scale up	"Deliberate efforts to increase the impact of successfully tested health interventions so as to benefit more people and to foster policy and program development on a lasting basis" (World Health Organization, 2010).
Reach	The absolute number, proportion, and representativeness of individuals who are willing to participate in an EBI (Glasgow et al., 2019).
Acceptability	Perception among implementation partners and collaborators that a given EBI is agreeable, palatable, or satisfactory (Proctor et al., 2011).
Fidelity	The degree to which practitioners deliver the intended intervention (Carroll et al., 2007).
Health Equity	Providing resources according to the need to help diverse populations achieve their highest state of health and other functioning. Equity is an ongoing process of assessing needs, correcting historical inequities, and creating conditions for optimal outcomes by members of all social identity groups (American Psychological Association, 2021).

The promise of IS is to reduce inequities and achieve health equity successfully and routinely. Community engagement leaders have not routinely achieved health equity, though there are numerous efforts in this area (e.g., Snell-Rood et al., 2021; Woodward et al., 2019). Part of the challenge is that many of the common approaches, principles, frameworks, and interventions used in IS have not had a clear foundational focus on health equity. Or they have not focused on raising community voices in such efforts (Brownson et al., 2021; Pinto et al., 2021). In addition, the number and complexity of models and frameworks can be confusing and challenging to navigate. For more information, the University of Colorado Denver provides a detailed description of the many IS theories, models, and frameworks (University of Colorado Denver, 2022).

The COVID-19 pandemic and the movement toward racial justice in the United States and globally have made structural barriers that create health inequities more visible (Bailey et al., 2021; Williams et al., 2019) Recent articles in IS highlight the critical role of community engagement and co-creation in promoting health equity (Baumann & Cabassa, 2020; Sánchez et al., 2021; Shelton, Adsul, Oh, et al., 2021). Equity-oriented implementation includes several equity components. These include incorporating explicit attention to the community's culture, history, values, assets, and needs in the principles, strategies, frameworks, and tools of IS (Baumann & Long, 2021). Equity-oriented implementation occurs through the implementation of EBIs that promote equity and address inequities in settings serving historically marginalized communities (Baumann & Cabassa, 2020). Community engagement provides the foundation, structures, and processes necessary for addressing root causes of health care inequities. Community engagement also helps create solutions and strategies that have promise in promoting health and equity (Shelton, Adsul, & Oh, 2021; Shelton, Adsul, Oh, et al., 2021).

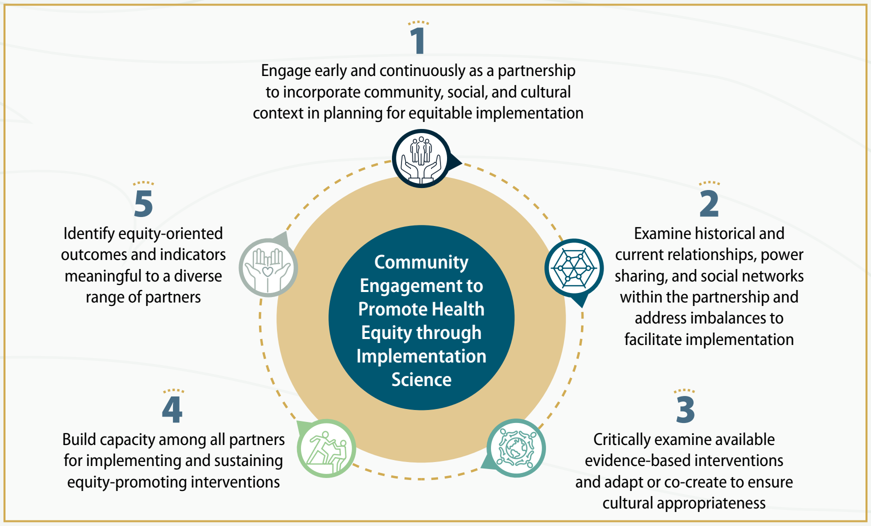
There is a long history of community organizing outside of academia and a robust literature on community engagement and CBPR (Israel et al., 2008; Michener et al., 2020; Minkler et al., 2012; Wallerstein & Duran, 2003, 2010, 2017). Recent work on participatory approaches and engagement reflect these and other influences in IS (Pinto et al., 2021; Ramanadhan et al., 2018). Community engagement efforts common in IS include a commitment to (Israel et al., 2008; Wallerstein & Duran, 2017):

1) **Taking action, supporting multidirectional learning, and helping with capacity-building to promote sustainability**
2) **Recognizing community values, strengths, and assets**
3) **Advancing community-defined problems, priorities, and solutions**
4) **Focusing on trust-building, respectful relationships, and diverse benefits**
5) **Assuring transparency and reflection on appropriate community engagement in decision-making, distribution, and sharing of power and resources**

There are also common challenges to effectively doing IS work. One challenge is recognizing the complexity and diversity of communities with respect to numerous factors, such as language and culture. Another challenge is the care IS practitioners should take in how they define a community.

Figure 9.1 outlines five pillars of community engagement for promoting health equity through IS. Though numbered, these activities are iterative and ongoing. In discussing the five pillars, we also highlight some core tensions to consider that have implications using community engagement to promote equity in implementation efforts.

Figure 9.1: Five Pillars of Community Engagement



1. Engage early and continuously as an academic-community team to incorporate community, social, and cultural context in planning for equitable implementation of interventions.

IS has a strong focus on context and understanding the influence of multiple socioecological factors. These factors include national and local policy, community, system, and interpersonal issues (Nilsen & Bernhardsson, 2019). Many IS frameworks are part of program delivery assessments, such as exploration of multilevel barriers and facilitators to inform and guide program implementation (Damschroder et al., 2009; Nilsen & Bernhardsson, 2019). However, community and social context have been missing in some IS studies and frameworks (London et al., 2020; Pinto et al., 2021).

In a recent review, Pinto et al. (2021) identified 74 IS models and frameworks that address community-level change related to communication, partnership exchange, capacity-building, leadership, and collaboration. The authors recommend more explicit definitions of community and partners; how they relate and engage with each other; and how researchers can engage with the community. They also noted community partners have not provided input into the development of many IS frameworks. IS leaders should cautiously use these frameworks or revise or adapt them with community input.

Clear definitions and descriptions of implementation processes and context are important if we are to understand community-relevant barriers and facilitators to implementation. Research and community partners may consider reflecting together during the selection, adaptation, and refinement of theories, models, and frameworks to inform implementation. For guidance, they may consider the following questions (Harvard Catalyst, 2021; Shelton, Adsul, Oh, et al., 2021; Woodward et al., 2019):

How are academic and community partners collaborating to define context and prioritize action items? Are we asking questions or prioritizing issues that are meaningful to the needs of the community? What channels can the partnership use to raise community voices and experiences? How can the partnership identify and uplift existing community strengths and assets?

Has there been attention to understanding the social and community context, including the historical and systemic forces of oppression and discrimination? How might these experiences affect community-engaged implementation efforts? How are we accounting for the role of structural racism, stigma, mistrust or distrust, social determinants of health, and economic and sociopolitical context?

How do power structures within community-engaged efforts affect implementation? What strategies encourage open discussions about historical and current power imbalances and ways to address them? How are research institutions and research teams demonstrating trustworthiness and building accountability? How do we distribute resources (e.g., time, funding, staffing), decision-making, and other forms of power across all partners?

How are we designing IS efforts to be inclusive and ensure fair access and participation for community partners? How can we support participation, and in what ways are dissemination plans transparent and accountable in reflecting community needs and goals? (Hoekstra et al., 2020)

Several equity-focused theories, frameworks, and models may be relevant for supporting community engagement in understanding the implementation context. Ideally, an IS partnership is established before implementation efforts. However, the contextual assessment offers a chance to identify key drivers of equal or unequal adoption, implementation, and sustainability of EBIs. As one example, the Health Equity Implementation Framework can help guide the identification of equity-oriented factors that may impede implementation of EBIs at the patient, provider, and system levels. This framework acknowledges experiences of discrimination or stigma. It uses qualitative methods to emphasize the experiences of historically and systematically marginalized populations (Woodward et al., 2019). The framework highlights the processes and structures through which community engagement can inform implementation. Engage for Equity focuses on health equity, partnerships, and addressing institutional racism (Engage for Equity, 2022; Sánchez et al., 2021).

It is important to collaborate with partners to select an approach to assess local community context and assets. Some methods show promise in promoting the engagement of partners in meaningful ways to develop trusting relationships, assure multidirectional communication, and amplify community perspectives in planning implementation efforts (Cabassa et al., 2014; Data Science to Patient Value Initiative, n.d.; Dopp et al., 2020; Joosten et al., 2015; London et al., 2020; Lyon et al., 2020; Matthews et al., 2018; Medina et al., 2020; Nease et al., 2019, 2020; Westfall et al., 2016; Whitney & Trosten-Bloom, 2010). These approaches demonstrate respect for both community and research expertise and value the lived experiences of community members while maintaining the scientific basis of EBIs. For example, the partnership can use appreciative inquiry alone or with other engagement methods to focus on understanding strengths, assets, successes, and possibilities of the community (Data Science to Patient Value Initiative, n.d.; Nease et al., 2020). Another engagement approach that prioritizes community voices is Boot Camp Translation. This approach translates evidence and guidelines into locally and contextually relevant action-based messages and materials for dissemination with community partners. Partnerships integrate such approaches to enhance communication, understanding, and improved health care for colon cancer, asthma, and hypertension (Data Science to Patient Value Initiative, n.d.; Norman et al., 2013; Westfall et al., 2016).

Human-centered design is an iterative engagement approach increasingly applied in IS. It involves brainstorming, coming to consensus, and seeking feedback that prioritizes the needs and values of community members. Human-centered design can inform any aspect of community engagement implementation (e.g., recruitment, dissemination, intervention, or strategy design). This approach takes a systems perspective and has strong potential to inform programs or strategies to address complex health inequities (e.g., community-driven approaches to reducing infant deaths) (Vechakul et al., 2015).

A community meeting. *Public Health Image Library, 2009.*

2. Examine historical and current relationships, power-sharing, and social networks within the partnership and address imbalances to facilitate implementation.

An important but often overlooked part of contextual assessments in IS is spending time in community settings to ensure that all partners understand historical and existing partnerships, relationships, coalitions, and networks. Identifying and connecting with existing networks helps avoid duplicated efforts. Such assessment might also highlight existing collaborations, partnerships, or coalitions that might enhance engagement and implementation efforts (Kavanagh et al., 2022; Valente et al., 2015). Mapping of networks, power structures, and partnerships can also help identify key influencers and messengers in the community whose support is necessary before embarking on implementation (Chapter 6).

It is also important to assess the nature of historical and ongoing academic research and community partnerships, engagement, and efforts. This is critical to ensure that the partnership can attend to personal or collective negative experiences with researchers, as well as mistrust and distrust of research and health/medical/public health institutions (Griffith et al., 2020). Understanding this history of relationships before implementation helps contextualize mistrust and community perceptions of lack of institutional trustworthiness (Shelton, Brotzman, et al., 2021), which likely serve as barriers to implementation. For example, in a case study below, a partnership used community engagement studios to initiate relationships in the LGBTQ+ community in New Mexico, identify appropriate communication strategies, and gather insights into implementation efforts for promoting cancer screening uptake. Learning who are the trusted sources, channels, and messengers valued by the community is equally important, as they may be essential partners.

A wide range of community-engagement efforts may be applicable in IS (Goodman & Sanders Thompson, 2017). It is important to be clear about the goal of the engagement effort and how engagement of partners will occur, that partnership roles align with community purposes and goals, and that participants feel supported and have minimal barriers (Sanders Thompson et al., 2021). Demonstrating trustworthiness along all phases of implementation requires that all partners are transparent in their intentions and benefit equally.

Shea and colleagues (2017) address nine domains that are important for IS researchers to consider as they form partnerships:

1) **Valuing community engagement in IS**
2) **Being open and introspective**
3) **Understanding the community**
4) **Valuing partner experience with and attitudes toward research**
5) **Supporting collaborative processes for decision-making**
6) **Co-designing research**
7) **Effectively communicating to diverse audiences**
8) **Sharing resources and successes**
9) **Contributing to a sustainable partnership**

Being aware of and attending to local economies, politics, and institutional relationships can also increase the likelihood of building a trusting and sustained partnership (Goodman & Sanders Thompson, 2017; Strode & Morris, 2021).

As a complement, community partners may wish to examine potential academic-community partners using criteria established by the Community Coalition for Equity in Research at Harvard (Harvard Catalyst, 2021). These criteria emphasize:

- Planning considerations (e.g., study goals, team composition, academic relationships, accountability processes)
- Recruitment and consent considerations (e.g., activities/materials are appropriate and accessible, involvement of trusted groups, appropriate incentives/compensation)
- Participation considerations (e.g., study design and outcomes are clear, participant burden is clear and minimizes harms, participation costs are covered, and measures and methods are inclusive)
- Dissemination considerations (e.g., plan includes both practice and community audiences, clear planning for returning of results that is timely and attends to partner needs, dissemination products are accessible, plans and budget support local partners in dissemination efforts)

Equity-focused, community-engaged IS work requires partners to examine and consider how and when to involve communities in research or implementation efforts collaboratively and explicitly (Baumann & Cabassa, 2020; Wells & Jones, 2009). Partners should consider whose voices are and are not represented (in terms of the diversity of community members and partners). They should consider how community values are upheld and how community benefits, harms, and unintended consequences are considered (Shelton, Adsul, Oh, et al., 2021). Researchers should be aware of the real or perceived uneven power dynamics and resources in forming partnerships. Researchers must be aware and intentional about how they will share resources, leadership, and decision-making. In addition, they should consider how structural racism and privilege may affect the development and sustainability of partnerships (Yonas et al., 2006).

3. Critically examine available evidence-based interventions and adapt or co-create to ensure cultural appropriateness.

IS often rests on the assumption that there is an existing EBI (with some proven level of effectiveness for improving a health behavior or outcome) that is not adopted and implemented among populations and settings that may benefit most from it. In many cases, IS efforts focus not on development of new treatments, guidelines, or interventions, but rather on delivery, adaptation, and sustainability of an existing program or practice. From an engagement and equity perspective, this has important implications. If an EBI is developed without the community's priorities, perspectives, values, and decisions, it is not likely to reflect their lived experiences (Health Experiences Research Network, 2019). In addition, widespread adoption and sustainability will likely be challenging (Bordeaux et al., 2021). Further, the well-resourced research settings where researchers typically develop and evaluate these programs do not often reflect racially, ethnically, and socioeconomically diverse communities. As a result, many EBIs may not be possible or appropriate for settings and populations that disproportionately experience structural barriers to health (Baumann & Cabassa, 2020; Baumann et al., 2019).

It is important that researchers, practitioners, and community members collaboratively examine, identify, and select programs to implement, particularly if the goal is to reduce inequities. Partners need to reflect on and consider what is evidence, for whom an intervention is evidence-based, and whether developing the intervention prioritizes diverse perspectives and voices (Shelton, Adsul, Oh, et al., 2021). Community engagement is essential from the beginning in designing EBIs that are relevant, acceptable, sustainable, and trusted (Wallerstein & Duran, 2006). Such an approach requires IS researchers to consider and possibly reframe where implementation efforts begin on the timeline leading to translation and to broaden what has historically counted as evidence. This may include community-defined evidence (e.g., evaluating the usefulness of existing community-led programs) and practice-based evidence from the local community that represents its culture and practices (Baumann et al., 2019; Green, 2008; Rycroft-Malone et al., 2004).

In some cases, EBIs may not exist that are a good fit or that reduce health inequities or address underlying structural factors that shape health and are a priority for a community (e.g., food insecurity, neighborhood violence). In such cases, partners may develop new or adapted existing interventions to address community concerns. For example, a community health worker program focused on increasing cancer screening may also address community priorities related to COVID-19 vaccination, housing, and food insecurity. Frameworks that clearly outline how to engage the community in the planning and delivery of the interventions can be helpful. For example, Transcreation is a framework for community-engaged behavioral interventions to reduce health disparities (Nápoles & Stewart, 2018) among other frameworks outlined above. Interventions are more likely to be successful in communities if they are co-created and prioritize intervention development with, for, and in the community with attention to flexibility, cost, feasibility, and partner strengths and priorities.

Engaging community members early in developing EBIs is consistent with CBPR and community engagement principles (Belone et al., 2016; Blue Bird Jernigan et al., 2015; Dickerson et al., 2020; Wallerstein & Duran, 2017; Walters et al., 2020). Such an approach necessitates consideration of whether the implemented EBIs are culturally centered and culturally derived (Dutta, 2007, 2018). This requires humility and recognition that there are many ways of knowing and evidence, including indigenous evidence and cultural evidence (Office of Indigenous Initiatives, 2021). For IS, approaches that put community at the center may also change the types of interventions implemented. These approaches may help incorporate community practices with potential for success and enable evaluation and rapid dissemination.

A focus on enhancing health equity will require greater prioritization of EBIs that target upstream structural factors (structural racism, social and economic context), including policy-level interventions. For example, Blue Bird Jernigan et al. (2012) used a participatory approach to identify structural barriers that shape food insecurity and to design and test policy interventions that result from a community-engaged needs assessment. A focus on equity through community engagement in IS also involves moving beyond implementing EBIs in health systems/clinical contexts to include community settings (churches, senior centers, juvenile justice settings, neighborhoods) and programs or policies that do not focus narrowly on health (e.g., improving environmental conditions, justice reforms, housing voucher or cash transfer programs, programs that build social capital and enhance neighborhood safety).

Historically in IS, there has been emphasis on the need to deliver EBIs with high fidelity to the original EBI. However, the dynamic contexts of implementation and acknowledgment increasingly consider that "one size does not fit all" (Hawe et al., 2009; Trickett et al., 2011). It may not be possible or even desirable for a partnership to deliver all components of EBIs with strict fidelity in different settings, particularly if the EBI was developed and tested in a context different from the implementation setting/population (Baumann & Cabassa, 2020; Cabassa & Baumann, 2013). When community partnerships select existing EBIs for implementation that they perceive as fitting with their local context (e.g., acceptable, culturally appropriate, doable), it still may be important to adapt the interventions to address social determinants of health and community needs. This may involve checking assumptions about how interventions work among community partners and reconsidering the function of program components (e.g., program delivery and the mechanisms through which they operate; Hawe, 2015; Perez Jolles et al., 2019).

4. Build capacity among all partners for implementing and sustaining equity-promoting interventions.

A community-engaged partnership must determine which EBIs to implement. Then, they have to consider how to get EBIs integrated into the practice setting (e.g., by training practitioners or changing community norms). Often, these are called implementation strategies, and useful compilations of these are available (Powell et al., 2015). However, there is an opportunity to bring more focus to equity and community engagement in the development, selection, and refinement of such strategies (Gaias et al., 2022).

Strategies that hold promise are those that increase trust, ownership, and community capacity. They build the capacity of partners to produce practices and research related to reducing health inequities (Shelton, Adsul, Oh et al., 2021). Community-engaged partnerships should develop and select strategies that address the most pressing barriers to implementation identified in the contextual assessment. The combined knowledge of community members, practitioners, and researchers offers the opportunity to match strategies to the drivers of implementation. Such enhancement of community and academic capacity can help sustain programs and partnerships.

An example of a community engagement partnership is the QuitSMART Utah trial. In this partnership, 11 community health center systems and 32 clinics engaged with researchers to increase the reach and impact of evidence-based tobacco cessation treatment delivered via quit-lines (i.e., telephone or web-based cessation services providing behavioral or pharmacotherapy interventions) (Schlechter et al., 2021). The engagement process consisted of:

- Developing a research-practice partnership
- Embedding liaisons within the partnership
- Creating patient and research advisory committees
- Assessing clinical workflow and usability
- Developing implementation strategies based on local context and prior findings

Such engagement processes allowed the study team to include diverse voices and patient perspectives in the design and delivery of implementation strategies.

When developing, selecting, and refining implementation strategies, IS researchers and community partners can learn from the literature on:

- Creating social change (Brown, 2017; Hooks, 2012)
- Social networks (Chapter 6)
- Organizational theory, including change agents, opinion leaders, and program champions (e.g., Shea, 2021) (Chapter 4)

If a shared goal of the partnership is to change or transform a context or system by implementing interventions to improve the lives of community members, it is important to nurture and support relationships among all partners (Brown, 2021). For partnerships to make sustained changes, community engagement and a centering of social justice are also critical.

As an example, partners in Massachusetts have been conducting capacity-building interventions for more than 10 years using a CBPR approach as part of the PLANET MassCONECT project. The goal is to train staff members of community-based organizations working with populations experiencing cancer inequities to find, adapt, and implement EBIs. Researchers and community coalition leaders collaboratively designed the initial curriculum to ensure that practice-based expertise and health equity were a focus. They grounded the work in an approach that included outcomes relating to health equity, improved service delivery, and (importantly) development of infrastructure to support future use of research evidence. As one examination of impact, the team conducted Social Network Analysis (SNA). The team found that, in one city, individuals with higher levels of engagement in the trainee communication network also had higher reports of using the EBIs. Yet, for two larger cities, the team could not sustain engagement in a way that supported participation in the network. This suggested that the team's ability to connect with and support an existing, strong network was critical to achieving the partnership's implementation goals. The PLANET MassCONECT example also highlights a need to take a systems perspective through co-design of capacity-building interventions. In that way, partners can develop solutions in the context of local networks and with a long-term view to supporting and sustaining knowledge translation for health equity (Ramanadhan et al., 2021).

5. Identify equity-oriented outcomes and indicators meaningful to a diverse range of partners.

A core activity in community-engaged implementation is to identify outcomes and indicators that matter to the diverse members of the partnership. This is critical for alignment of action, investments in the partnership, and actions to build sustainable interventions (Camillus et al., 2021). A useful starting point can be a collaborative planning process to identify the key partners who will affect and be affected by the adoption, implementation, and sustainment of an EBI. A mapping tool, typically referred to as "stakeholder mapping," helps academic and community partners to identify an inclusive group of partners. Then, the team can assess the needs of key partners to help identify outcomes they can track and target for change. It is important to recognize that various outcomes might be important to various partners, including:

- Implementation outcomes (e.g., reach, acceptability, cost, sustainability, other)
- Community outcomes (e.g., capacity for program delivery, infrastructure and resources, unintended consequences)
- Social justice outcomes (e.g., removing structural barriers to health equity, reduction or elimination of health inequities)

Community-engaged implementation often requires refining of outcomes as well as measurement of longer-term, systems, social, or community-level outcomes that do not always match with timelines and research objectives (Springett, 2017). A solution to address this may be having shorter-term outcomes linked to initial reporting efforts and broader outcomes linked to overall impact assessments. It is also critical that researchers regularly share data with the community. Researchers should consider the extent to which implementation efforts reduce or worsen inequities. Several recent articles provide examples of being accountable in tracking equity in implementation indicators and outcomes in a way that is meaningful to all partners (Baumann & Cabassa, 2020). This includes a recent extension of the RE-AIM model (Reach, Effectiveness, Adoption, Implementation, and Maintenance, Shelton et al., 2020).

Additionally, we must consider, prioritize, plan for, and measure the sustainability of partnerships, programs, and impact from the start of all community engagement efforts in IS (Shelton et al., 2017). This has important implications for building and maintaining trust among community partners. An example of such prioritization is The National Witness Project. The National Witness Project is an NCI-recognized, evidence-based cancer control program developed nearly 30 years ago. It was developed in partnership with African American cancer survivors to address inequities in breast and cervical cancer screening and mortality, particularly in light of the stigma and discrimination they experienced in accessing health care (Erwin et al., 2003; National Cancer Institute, 2020). The program builds on the strengths of the community by training African American lay health advisors (LHAs, peers from the community) to educate, navigate, and help cancer survivors share powerful narratives to promote breast and cervical cancer screening and timely follow-up. Despite its national dissemination and implementation for more than 25 years in a range of community-based and academic/medical settings, The National Witness Project faced numerous challenges to sustaining program delivery (Shelton et al., 2017). Over the past 11 years, The National Witness Project partnered with researchers to understand more about the multilevel barriers and facilitators that affect sustained impact, delivery, and infrastructure of the program and retention of LHAs. Together, they developed a community-informed LHA Sustainability Framework tested nationally at 16 sites (Shelton et al., 2017). Early findings suggested that academic and community partnership resources are important for sustainability. The partners use tools like the Program Sustainability Assessment Tool (Luke et al., 2014; Washington University in St. Louis, 2021) to guide both reflection and data collection. Such tools can help identify areas that need strengthening to sustain programs, such as ongoing training, partnerships, sustained and diverse funding, and political support. These tools can also identify relevant indicators of sustainability outcomes, such as continued delivery of group sessions, the number of active LHAs, and the number reached, educated, and navigated. The partners use data to inform practice and to develop, refine, and test strategies to actively support sustainability.

Chapter Conclusion

Community engagement is critical for successful implementation, especially if a goal is equity. Implementation efforts to address health inequities and power imbalances are hard work. Implementation occurs within a broader system and societal context that is inequitably structured. Only by carefully examining and reflecting on historical and systemic forces at play when implementing EBIs will community-engaged partnerships effectively engage in equity-promoting work (Baumann & Cabassa, 2020; Shelton, et al., 2021).

The five pillars of community engagement to promote health equity through IS help achieve success. Such skills are often missing from traditional research training programs. Research training needs to incorporate ongoing efforts to build capacity for equity-oriented and community-engaged IS (Baumann et al., 2022; Shea et al., 2017). Implementation efforts must also be flexible to address the gap between research and practice that currently exists and to address health inequities. For historically and systematically marginalized communities, engagement is essential to incorporating community voices within research processes and throughout all aspects of implementation efforts (Adsul et al., 2022). To make progress in these areas, implementation research, community engagement, and health equity need to work together (Adsul & Chambers, 2019). We need to emphasize measurement of partnership processes and outcomes to strengthen community engagement and its value for implementation efforts and IS.

Case Study: Community Engagement Studios with Sexual and Gender Diverse Individuals in New Mexico

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Evaluation Question/Issue

To assess cancer prevention behaviors among sexual and gender diverse communities in New Mexico, we conducted a cross-sectional survey from January–March 2021. The survey received more than 2,000 responses. Over 75% of respondents asked to stay engaged with the study.

Challenge

Despite the positive response, research team members felt unsure how best to engage systematically underrepresented sexual and gender diverse individuals. The primary investigator was at an early stage of career and had limited relationships with the members of the community.

Response

The UNM CTSC CERC team had recent training by the Meharry-Vanderbilt Community Engaged Research Core in conducting community engagement studios. The CERC collaborated to conduct a community engagement studio as the first step toward ongoing community engagement.

Promising Practice

The goal of the community engagement studio was to understand how best to connect with the respondents of the online survey and with the LGBTQ+ community as a whole. A secondary goal was to begin understanding how best to implement interventions to promote cancer screening among these communities. At the meeting, the research team also presented a draft of an infographic as an example to communicate with sexual and gender diverse communities in New Mexico. Studio participants, referred to as community experts, were previously recruited through established CERC connections and through local organizations relevant to this population who helped distribute flyers electronically to their networks. A total of 11 community experts attended a two-hour discussion with the research team, facilitated by CERC.

Lessons Learned Led to Strengthening Community-Partnered Evaluation

The community engagement studio led to robust discussions around the study, engagement processes, and communication strategies. When asked about engagement, community experts described their preferences in not using "sexual gender diverse communities" because they did not identify with the term and instead preferred "LGBTQ+." Several mentioned the need for quick, relevant communication materials for engagement (e.g., a 60- to 90-second video [Tik-Tok, YouTube, Instagram/Facebook] or infographic with a QR code). Overall, the group suggested engaging young adults early in cancer prevention, educating clinicians on the importance of pronouns and being inclusive, collaborating with clinics that have direct trans and queer health care provision experience, and addressing medical provider bias against the community. Most community experts expressed interest in continued related discussions.

Take-Home Messages

The community engagement studio provided detailed and constructive feedback regarding the communication strategies and highlighted future implementation considerations.

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Appendix 9: Accessible Descriptions for Complex Graphics

Figure 9.1—Five Pillars of Community Engagement

Figure 9.1 shows a circle surrounded by 5 activities, known as five pillars of Community Engagement to Promote Health Equity through Implementation Science. The 5 pillars are:

1) Engage early and continuously as a partnership to incorporate community, social, and cultural context in planning for equitable implementation
2) Examine historical and current relationships, power sharing, and social networks within the partnership and address imbalances to facilitate implementation
3) Critically examine available evidence-based interventions and adapt or co-create to ensure cultural appropriateness
4) Build capacity among all partners for implementing and sustaining equity-promoting interventions
5) Identify equity-oriented outcomes and indicators meaningful to a diverse range of partners

◀ *Return to Figure 9.1*

CHAPTER 10: SUSTAINING THE ENGAGEMENT—TOOLS AND PARTNERSHIPS

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Background

This chapter features community engagement among communities that bear a disproportionate burden of environmental issues. These communities collaborate and partner with the Agency for Toxic Substances and Diseases Registry (ATSDR). ATSDR is a federal public health agency of the U.S. Department of Health and Human Services. ATSDR's headquarter office is in Atlanta, Georgia. ATSDR has with regional offices across the United States. ATSDR has a congressional mandate to:

- Perform public health assessments at contaminated sites
- Develop toxicological profiles on harmful substances
- Conduct epidemiological studies
- Maintain health registries
- Conduct medical surveillance

Engaging communities affected by environmental contamination is fundamental to all of ATSDR's work. We often work directly with community partners. The examples provided in this chapter reflect four activities to acknowledge and address environmental injustices in environmental public health work and community engagement practice:

1. **Addressing power imbalances.** Partnering organizations should define and ensure that they base their roles on organizational expertise and capacity, with respect for their unique contributions. Determine whether historic and/or systemic imbalances afford some partners more privilege than others. Encourage external advisors to act with humility and focus on what they can learn as well as what they know.
2. **Expressing cultural identity in the work to sustain relationships.** Respecting and understanding communities and their culture is critical to developing the respectful relationships needed to drive change and maintain community engagement. Public health practitioners must recognize individual and collective trauma and systemic oppression among communities to nurture relationships in a meaningful and respectful way. Professionals often need to be aware of their cultural assumptions and be open to the challenge of revising them.
3. **Building and earning trust and trustworthiness.** Starting points for developing trust and trustworthiness include empathy and respect, consistency, self-awareness, and awareness of one's role in systems. Without mutual trust in partnerships, engagement may not occur. Partners earn and may not assume, trust and trustworthiness.

4. **Identifying the levers to push for the most systemic change.** Community members often hold lived knowledge of the most effective avenues for systemic change, simply by observing how social systems interact with their efforts to improve residents' lives. But some may lack the political power to instill systemic change. Prioritizing equity often serves as a crucial systems tool. Training leaders in community engagement through an equity-focused lens can build capacity to help drive maximal change in which the community's needs and visions come first.

In this chapter, we share several examples of integrating the above themes alongside the principles of community engagement. We demonstrate these themes through activities of ATSDR's National Land Reuse Health Program (Land Reuse Program) and in a community health education project on the Navajo Nation. The examples shared show how the state of the environment impacts social determinants of health.

Environmental public health professionals and community members come together around environmental restoration, community education, and community revitalization to sustain and improve long-term community health. This cooperation also improves community connections through rich, long-lasting relationships and collaborations. Sustaining relationships through community engagement is crucial to maintaining the trust earned over months and years of collaboration on community revitalization initiatives. Collaboration may be internal to the community, with some external assistance to build capacity to sustain interpersonal and local relationships to move toward revitalization. Or, it may be external to the community, such as through a collaborative partnership over the long term. The revitalization community that forms may range from local residents to city administrators to university or agency partners. This partnership can result in long-term, even lifelong, bonds which can draw resources into the community.

Staying the Course: Fostering Long-Term, Sustainable Relationships and Community Engagement through ATSDR's National Land Reuse Health Program

ATSDR's Land Reuse Program focuses on environmental improvement and environmental justice. The program celebrates wins by sustaining action while earning and building trust among communities. Typically, communities invite us to provide technical assistance about health effects from living near contaminated properties. In our partnerships, the community vision and concerns come first. The Land Reuse Program recognizes community members as the true experts who can drive health-focused revitalization. This helps avoid power imbalances.

The Land Reuse Program has created several tools and resources to educate communities and the environmental health workforce. Our tools and resources focus on how to identify, characterize, and assess impacts of land reuse sites and brownfields. These sites are often vacant, potentially contaminated, or incompatibly located. Two of the most-used tools include the Environmental Health and Land Reuse (EHLR) Certificate training and the ATSDR Action Model.

EHLR Training. The EHLR training offers a certificate and continuing education hours. It has a broad focus on:

- Community engagement
- Evaluating environmental and health risks
- Communicating risks
- Redesigning communities with health in mind
- Measuring environmental and health change (Agency for Toxic Substances and Disease Registry, 2022)

Action Model. The ATSDR Action Model is a four-step model to engage communities in land reuse and revitalization projects. It incorporates community-defined public health indicators to track over the course of redevelopment (Agency for Toxic Substances and Diseases Registry, 2019). Using the ATSDR Action Model helps build lasting relationships among community redevelopment partners—the development community—and provides a strategy for ongoing collaboration.

ATSDR's Land Reuse Program has provided technical assistance nationally to communities with a disproportionate burden of contaminated sites and concerns about potential adverse health impacts. The program has its own community of revitalization experts, the Brownfields & Reuse Opportunity Working Network (BROWN). BROWN members include (among others) filmmakers, public health practitioners, regulators, academics, community leaders, and environmental consultants. For several years, BROWN has provided free consultative assistance to communities through its Community Partnerships program (Agency for Toxic Substances and Diseases Registry, 2021). Eight community partnerships are long-term, and all continue to this day. Much of BROWN's technical assistance occurred early in the projects. Each project has benefitted from additional funding or support. The community partnerships, summarized below, incorporate some to all principles of community engagement. This chapter highlights two community partnerships in the Missouri Bootheel and the Navajo Nation. They are written by community champions who practice and sustain community engagement through deep understanding of their culture and community.

Summary of ATSDR and Brownfields & Reuse Opportunity Working Network (BROWN) Community Partnership Projects

Andrews University Center for Excellence in Environmental Health is a university-led collaboration in Berrien Springs, Michigan. The partnership raises awarenessand understanding about the impact of the environment on overall community health in Berrien County, Michigan. The partnership hosted a soilSHOP (Soil Screening, Health, Outreach and Partnership) and children's blood lead screening event. They are also developing a community guide highlighting the environmental and health landscape of Berrien County.

The Arizona Healthfields Initiative (AHI) is a statewide network of individuals and agencies dedicated to a land use project to reuse potentially contaminated lands to improve community health—a Healthfields approach. In 2016, the project expanded into another community partnership in the Navajo (Diné) Nation. Activities included providing environmental health training at Diné College for several years. The Navajo Nation partnership also offers free technical assistance with planning and visioning sessions for redevelopment projects. In 2019, the partnership completed a free environmental site assessment for the Chinle Chapter. In 2022, the partnership hosted a soilSHOP (Soil Screening, Health Outreach, and Partnership) with the Red Lake Chapter.

Baker City, Oregon's Baker Technical Institute High School is home to a project led by a high school class and their environmental science teacher. The students oversaw the assessment of brownfields properties, created site inventories, and become local champions. Baker School District hosts the only high school-run brownfield program in the country. Students raised brownfield awareness and used ATSDR's Site Tool to help the city write a Community-Wide Brownfields Assessment Grant.

Howardville Community Betterment Committee (HCBC) in Howardville, Missouri, received a brownfields cleanup grant to clean up and repurpose the old Howardville School. In 2016, HCBC obtained additional funding for community revitalization efforts, including the Howardville School project. In one community event, BROWN members collaborated with community partners to provide free health screening, children's blood lead level screenings, and soil screenings for lead (i.e., a soilSHOP).

From 2016–2019, Howardville Community Betterment and ATSDR's Land Reuse Program jointly received Robert Wood Johnson Foundation funding to further revitalization efforts in three communities. We worked in the Missouri Bootheel, Navajo Nation, and in Marquette County, Michigan. In 2021, with the assistance of a BROWN partner, Howardville Community Betterment received a grant to continue cleaning up and repurposing the Howardville School.

Jacksonville Health Zone 1 is a project to engage community members in the cleanup of contaminated land reuse sites. The Jacksonville pilot partnered with Florida Health–Duval County, who inventoried 139 land reuse sites, including 7 Superfund sites and more than 100 brownfields. Florida Health–Duval County collaborated with local partners to help create a land reuse/brownfields curriculum to educate residents. They also participated in two soilSHOP events and followed up with residents who had high levels of lead in garden soil.

The K.I. Sawyer Community Alliance (SCA) in Sawyer, Marquette County Michigan, is creating a sense of community in a repurposed air force base. The project benefitted from Robert Wood Johnson Foundation funding in partnership with BROWN members. The collaboration conducted a community needs assessment and food access survey to create a mini master plan for community development and increased food access. In addition, SCA helped create a food truck grocery store pilot.

Navajo Nation Healthfields is a Healthfields approach to land reuse. The Navajo Nation benefitted from Robert Wood Johnson Foundation funding from BROWN member efforts. The partnership launched the Healthfields Redevelopment Coalition to target three areas with large numbers of land reuse sites. A BROWN partner obtained federal funding to develop plans for a vendor crafts village. They also received additional federal funding for revitalization projects in other areas of the Navajo Nation. With funding assistance facilitated by a BROWN partner, the Navajo Nation EPA has overseen four asbestos removals from a former sawmill. In addition, ATSDR and BROWN members have partnered with Diné College for several years to provide an environmental health and land reuse summer curriculum to train the future environmental health workforce.

North America-Eastern Europe Brownfields Working Group is an international collaborative. BROWN, new partners, and Oradea University in Romania share best practices, resources, and knowledge about land reuse and redevelopment. Through this collaboration, Oradea University won a grant to sponsor an exchange program, during which one BROWN partner engaged with Oradea faculty. In partnership with ATSDR's Land Reuse Program, an Oradea faculty member completed a Fulbright Fellowship to study land reuse and redevelopment with the University of Illinois. In 2021–2022, the Journal of Environmental Health featured thre e manuscripts on land reuse as a product of the working group. In 2023, the collaboration won funding from North Atlantic Treaty Organization to host an international Advanced Research Workshop on the sustainable reuse of military brownfields in Ukraine.

Case Study: Traditional Ecological Knowledge and Western Science through a Partnership with ATSDR and BROWN

During the summers of 2019 through 2022, Diné College partnered with ATSDR's Land Reuse Program to provide ATSDR's Environmental Health and Land Reuse (EHLR) training to a cohort of students in the Dine' Summer Internship Program. The Summer Internship Program is part of a National Science Foundation and Tribal Colleges and Universities Program grant. The program consists of 10 weeks of summer course training—both in classroom and field activity—using hypothesis-driven scientific methodology approaches.

Diné College faculty and environmental specialists mentor students to develop a hypothesis and guide them through designing their own research experiment. The students spend the first three weeks in classroom training that immerses them in Tribal Ecosystem Knowledge and culture. Then, the program provides the students with the tools to conduct research. The integration of Diné Traditional Ecological Knowledge was challenging in the ATSDR EHLR course. However, we blended the instructional team to ensure the introduction of Native science and traditional environmental science. This produced a unique version of the ATSDR curriculum. Figure 10.1 highlights one of the EHLR training field activities that integrated Tribal Ecosystem Knowledge with Western science.

The EHLR course brought together Native and Western science, technology, and traditional wisdom in environmental health and land reuse to STEM (science, technology, engineering, and mathematics) students. It advanced collaboration with Western science practitioners while deepening the commitment to pass on to future generations Native science and culture. This ensured the sustainability of culture, relationships, and interconnectedness.

Over thousands of years, Diné Traditional Ecological Knowledge is used and passed down largely through oral traditions. There exists a great opportunity to bring together modern technology and traditional wisdom to support Diné people and provide a modern and sustainable lifestyle in a healthy environment that respects and honors earth.

Figure 10.1

Diné College summer class of 2022, participating in a soil sample screening and community health event with Red Lake Chapter #18 in Navajo, New Mexico. *Image taken by ATSDR, 2022.*

Sustaining Engagement by Integrating the Navajo (Diné) Tribal Ecosystem Knowledge and Western Science

A meeting with a community leader in Navajo Nation. *Lloyd Degrane, 2019.*

Western science tends to segregate the secular from the spiritual. Native science does not. It combines and complements all aspects of well-being, a truly holistic approach. The (Navajo) Diné elders' explanation of the ancient ways, the ways of nature, pathways through life's journey, is engrained in guiding oral stories of the people. The word "Diné" in the Navajo language means "the people." At the beginning of Diné College's Summer Internship Program, a respected Traditionalist, a Medicine Man, performs the sacred ritual of the Protection Way ending with the Beauty Way ceremony. This is to protect the students, staff members, and faculty from environmental disruptions, toxics, and imbalances as they engage in Western research activities. They retain critical balance and harmony in an equilibrium state of Ho'zho: In Beauty I Walk.

The Diné concept of and relationship to their environment and the natural elements of life strongly link to ancient Diné principles and values which must guide community engagement, risk assessment, and risk communication. To effectively apply these, Western researchers and educators must understand some basic rules:

- Diné traditional belief is that illness and imperfection of life are directly related to an imbalance in their lives.
- Toxins and toxics disrupt the balance of Earth and Sky and therefore are disrespectful to Mother Earth.
- Holistic healing is maintained by the interconnectedness among physical, emotional, psychological, and spiritual existence.
- Harmony between these elements is essential.
- Great respect for speech and thought processes, responsibility, and accountability, are implicit in communications.

It can be challenging to blend Diné principles and values with Western science. Through our collaboration, we provided an enriching learning environment for our students and each other.

A view of the painted desert in Navajo Nation. *Lloyd DeGrane, 2019.*

Sustaining Engagement in the Missouri Bootheel

A community leader in a public meeting in the Missouri Bootheel. *Lloyd Degrane, 2019.*

Far Southeastern Missouri has a shape like the heel of a boot, hence the name "Missouri Bootheel." Howardville was founded as a town for black farmers. It is located in the center of the Bootheel. The Howardville School closed in 1985, and the building was used for different purposes until it became vacant and deteriorated.

Many former students reunited through the Howardville School and the superior education received there. This forms and sustains long-term collaboration and common goals. For example, several former students answered the call of the Howardville Community Betterment Committee (HCBC) to create the Howardville School Restoration sub-committee under the umbrella of the HCBC. They fundraise and pay annual dues to assist with the restoration of the Howardville School. As an ad hoc committee, once the Howardville School has been restored, the subcommittee will dissolve and come right back up as the Howardville School Sustainability Committee. Their funds will be explicitly used for maintenance, housekeeping and prevention of systems breakdown, through an Operation and Maintenance Plan. The City of Howardville received funding in 2013 to remediate asbestos contamination and lead-based paint from the Howardville School. The HCBC provided Environmental Job Training classes.15 students received instruction at the site of the Howardville School. They became state certified and became employed to help remediate asbestos and lead at the site of the Howardville School, promoting local source hiring. The Howardville School was nominated to the National Historic Register by the HCBC on September 5th, 2017 and was listed to the National Register of Historic places on November 22, 2017.

In 2016, the ATSDR-BROWN-Howardville partnership won a team award to be Robert Wood Johnson Foundation Culture of Health Leaders. As Culture of Health Leaders, we spent three years steeped in trainings focused on equity, diversity, and inclusion. The training enhanced community engagement and served as a lever to prioritize equity and drive community change.

Howardville and other Bootheel communities commit to sustainable relationships and community engagement. They build trust, earn trust, and work on a level ground with many partners. They implement all 10 principles of community engagement throughout their work. This helps to sustain community, partners, relationships, and engagement.

An old cotton gin in the Missouri Bootheel. *Lloyd DeGrane, 2019.*

Tools for Sustaining Community Engagement

ATSDR maintains a variety of tools and resources to support public health practitioners engaging communities over the course of environmental health responses. These tools incorporate a focus on unique cultural identities, histories, and current needs of communities. We highlight five key resources, below.

Selected ATSDR Tools for Engaging Communities over the Course of Environmental Health Responses

ATSDR Community Engagement Playbook

The playbook outlines a framework to guide practitioners through phases of community engagement over the course of an environmental public health response:

1) **Setting the stage**
2) **Getting started**
3) **Keeping it going**
4) **Wrapping up**

One section of the playbook contains a menu of activities that build trust and credibility between the public health team and community members while also advancing community health. Each activity section points the practitioner to further resources to enhance their practice, including the ATSDR Communication Toolkit. The glossary and resource sections introduce advanced practice topics.

ATSDR Communication Toolkit

The toolkit offers 18 tools and templates that help practitioners learn about the community, outreach, and evaluating communication efforts. A central idea is that initiating and maintaining two-way information-sharing and dialogue enables effective communication and is critical in fostering trusting relationships. Even before initiating community engagement, practitioners can begin to gather information from the community. Half of the featured tools help the practitioner understand local history and context, enhance cultural understanding, learn local preferences, and interact with empathy. Other tools coach on sharing information with the community. These include the guide to materials development, message mapping, community meeting guidelines, presenting to the community, and tips on continued contact during the assessment period.

ATSDR Environmental Health and Land Reuse (EHLR) Certificate Training

The ATSDR EHLR training builds capacity of environment and health professionals; planners; community members; and students in environmental science, public health, and planning to engage in health focused (Healthfields) redevelopment. Each module of the EHLR Classroom Training represents one step of ATSDR's 5-step Land Reuse Model:

1) **Engaging with Your Community**
2) **Evaluating Environmental and Health Risks**
3) **Communicating Environmental and Health Risks to the Community**
4) **Redesigning with Health in Mind**
5) **Measuring Success**

While community engagement is a stand-alone module, it is integral to all five modules.

ATSDR Brownfields/Land Reuse Action Model

The ATSDR Brownfields/Land Reuse Action Model is a framework to support diverse members of the development community to find ways to make health part of the renewal process. Officials, developers, community supporters, and residents can use the action model to identify common goals to incorporate into strategic planning.

ATSDR Community Stress Resource Center

The experience of living with chronic environmental contamination can be psychologically stressful for community members (Sullivan et al., 2021). Reasons include uncertainty, social conflict, and health (Gerhardstein et al., 2019). How public health practitioners build and sustain relationships with communities matters. This can contribute to the stress experience, or it can bolster community resilience. The Resource Center outlines three key steps—recognize, partner, and prepare—for supporting communities in responding to psychosocial issues related to environmental contamination. In addition to the three keys, the Resource Center discusses:

- The science of stress and environmental contamination
- Sharing of scientific literature on stress and environment with a sortable library of practice-based resources

The Resource Center also includes a training module and delivers action-oriented tips, fact sheets, a video and more for practitioners working directly with communities.

Chapter Conclusion

In this chapter, we provided a glimpse of how ATSDR and partners build and maintain sustainable relationships:

- Integrating principles of community engagement to address power imbalances
- Expressing and respecting cultural identity
- Building trust and trustworthiness
- Identifying the tools to use for the most systemic change

Trusting and sustained relationships enable the time and space for individuals to express cultural identities and for those identities to affect how the public health response unfolds. It may start simply, using culturally appropriate images and language in public health content. Then, it may deepen in the pursuit of more complex, systemic changes that empower communities to improve health outcomes and reach for their goals.

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AFTERWORD: THE PROMISE OF COMMUNITY-ENGAGED RESEARCH

Each decade, we revise the Principles of Community Engagement to reflect the changes in practice and the progression of community-engaged and community-based science and research. The third edition provides approaches, frameworks, and examples that demonstrate the powerful changes made possible when communities across the nation and the world come together for better health.

It has been the honor of a lifetime to lead this edition. It is a legacy work for many of us. We hope that this can serve as a guide for investigators new to the field and those seeking to advance their practice.

The future is promising for community-engaged research. Models such as Emancipatory Research, rooted in critical theory and embracing a wide set of research methods (e.g., narrative, arts-based, participatory, embodied, and action-oriented), demonstrate how we can construct research to balance social power and privilege and advance social justice. Bringing such methods to the forefront can create a more just and equitable society.

We align this edition with Healthy People 2030 (HP 2030), U.S. guidance that sets data-driven national objectives to improve health and well-being over the next decade. As such, we strongly support the adoption of strength-based approaches and activities that enhance social cohesion. HP 2030 adopted civic participation as a core research objective (representing a public health issue with a high health or economic burden or significant disparity). Involvement and investment in our communities enhances social cohesion. We recognize activities such as participating in civic groups, running for school, local and state boards, and engagement in our electoral processes, as ways of exercising agency and contributing to our well-being. These are solid and positive pathways to ensuring the health of our nation.

Lastly, our moral and ethical contributions to our nation can't stop at measuring and documenting disparities. As researchers and community members, we must commit to addressing the upstream and downstream causes. To quote Nanette Wenger, MD, who studies women's health, we must "investigate, educate, advocate, and legislate" to address the issues affecting our health at every level. We call on investigators and researchers to work with communities to identify priority issues and solve them, including advocating for policy, structure, and system changes.

As science evolves, we hope to see our nation's health restored, renewed, and equitable. This edition honors the communities and researchers who have dedicated their careers to a better future.

Elizabeth Cohn, RN, NP, PhD, 2024

Volunteers tending a community garden.