UPLIFTING CONTEXTUAL AND EXPERIENTIAL EVIDENCE:

PROMISING PRACTICES & RECOMMENDATIONS

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WHEN NUMBERS DON'T TELL THE WHOLE STORY: COMMUNITY PERSPECTIVE AS EVIDENCE

Shared by an academic researcher based in Houston, Texas, the following story about resident engagement in community safety research illustrates the value of harnessing multiple forms of evidence.

While leading a community health data project at a local university, a research team looked at law enforcement data on community safety and quickly identified a few blocks within a neighborhood adjacent to Houston's downtown area with a high volume of 911 calls. Based on media stories and crime trends, the team was not surprised, but was curious about the concentration of 911 reports in a few specific blocks.

The research team included individuals that were trained and prepared to conduct in-person interviews in the community to understand their perceptions of safety and crime. Many of the researchers were from the community of interest or familiar with the area.

The interviews acknowledged a history of violence in the area, as well as current concerns among neighbors regarding community safety, rapid displacement that accompanied gentrification of the area, and that police were not responsive to calls from their neighborhood. Several retirees involved in a local civic club agreed to be vigilant to any suspicious activities and to make reports to 911 consistent with the national "See Something, Say Something" campaign.

While the research team initially interpreted the law enforcement data as evidence of elevated risk and crime in the community, when paired with contextual information collected through observations and interviews, the increased 911 calls became reframed as evidence of a protective community response. Law enforcement data was a starting point – prompting questions that led to additional data collection – but ultimately incomplete on its own.

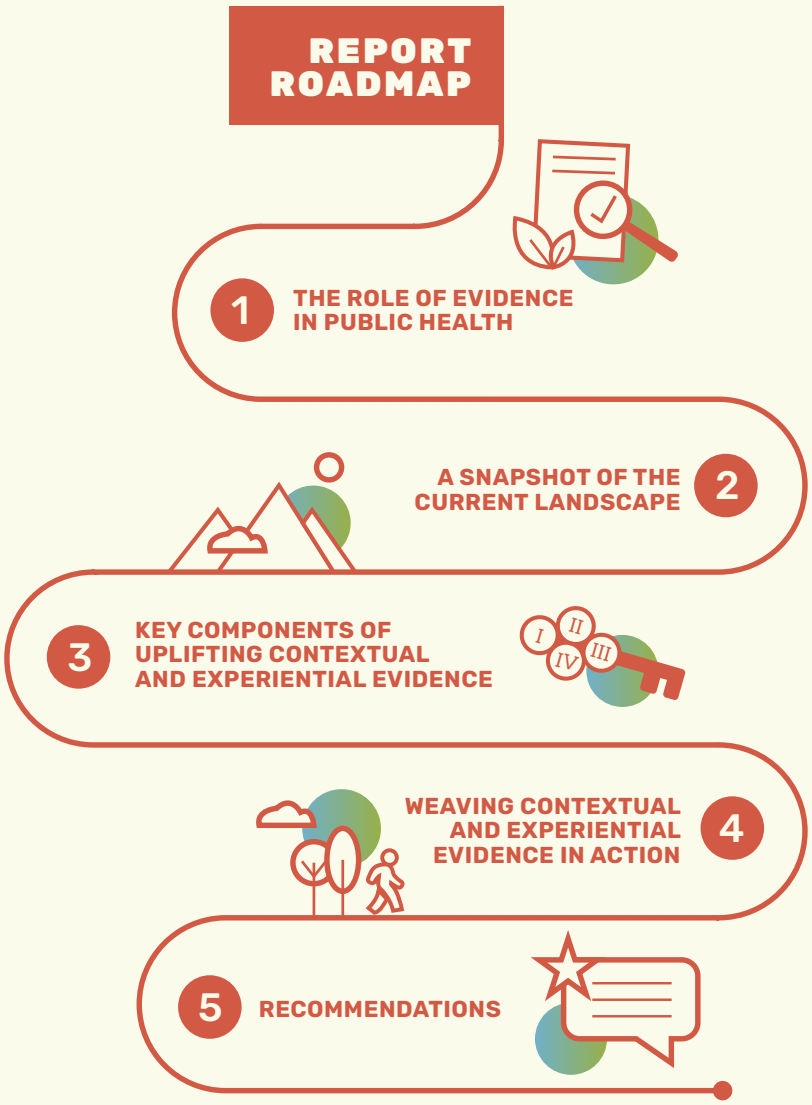
Trusted community researchers listened to residents' perspectives and contextualized their responses to better understand the trends seen in the empirical evidence. This weaving of different forms of evidence ultimately led to a community-informed perspective on safety and laid the groundwork for shared solutions across neighbors, law enforcement, and researchers.

What could have been described as one of the most dangerous blocks in the area was actually a cornerstone of neighborhood strength.

REPORT AT A GLANCE

As evidence-based approaches to funding and practice become the standard in the public health field, it is increasingly important to define what constitutes credible and valuable evidence beyond peer-reviewed, scientific literature. The Centers for Disease Control and Prevention (CDC) outlines three forms of evidence that must work together to inform decision making: best available research evidence, contextual evidence, and experiential evidence.[1] Uplifting contextual and experiential evidence alongside best available research evidence contributes to a balanced approach for making decisions about funding, strategies, policies, programs, and long-term planning.

This report intends to (1) illustrate the value of uplifting contextual and experiential evidence, and (2) highlight promising practices for generating and sustaining contextual and experiential evidence to inform decision making. To do so, the report:



1. Summarizes the current role of evidence in the public health field, including the field's overreliance on best available research evidence,
2. Describes method for conducting a landscape scan that identified relevant frameworks, tools, and approaches,
3. Presents four key components and associated strategies for gathering and sustaining contextual and experiential evidence,
4. Showcases an example from the environmental justice field that illustrates the use of multiple forms of evidence, and
5. Outlines recommendations on how different public health sectors—federal agencies, local and state health agencies, community-based organizations, academic researchers, and philanthropy—can wield their power to champion contextual and experiential evidence.

This report serves as a conceptual and practical tool for understanding contextual and experiential evidence, but does not provide guidance on how to integrate the three forms of evidence to make specific decisions. Each community has unique circumstances with different needs, assets, and priorities that may not be reflected in the approaches shared in this report.

1 THE ROLE OF EVIDENCE IN PUBLIC HEALTH

Evidence-based practice (EBP) in public health – which privileges study designs like randomized-controlled trials (RCTs), systematic literature reviews, and meta-analysis – has been used to demonstrate the effectiveness of programs, policies, and practices.[2] While EBP has several shortcomings, including limited integration of community engagement and sociocultural contexts,[2] decision-makers rely on EBP to make data-driven decisions and allocate resources on what has been proven to achieve intended results. The Health Resources and Services Administration saw a 43.4% increase in the use of the term "evidence-based" in funding opportunities between 2008 and 2021.[3] The increased significance of evidence in public sectors, especially as a gateway to funding and community-level change, underscores the urgency of clarifying what constitutes credible and valuable evidence. To guide decisions that equitably benefit the breadth of populations served by public health, it is imperative to look beyond traditional peer-reviewed, published scientific literature for evidence.

CDC's Framework for Thinking about Evidence[4] describes three types of evidence that are critical in decision making for funding, strategies, policies, programs, and long-term planning (Figure 1):

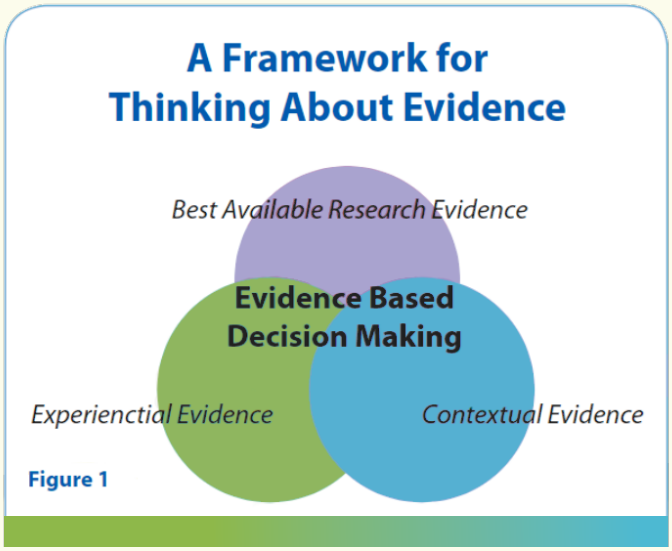


Figure from Understanding Evidence Part 1: Best Available Research Evidence. A Guide to the Continuum of Evidence of Effectiveness, CDC.[5]

1. **BEST AVAILABLE RESEARCH EVIDENCE**[5] refers to evidence produced through scientific inquiry and process, often presented through published, peer-reviewed literature. This evidence employs methodologies like randomized-controlled trials, meta-analysis, systematic reviews, and other experimental designs to measure the design, fidelity, and replicability of interventions.

2. **CONTEXTUAL EVIDENCE**[6] refers to measurable factors gathered from local and community data sources to understand how community context and characteristics will impact the implementation, usefulness, and acceptability of a strategy or decision. This evidence includes various types of data about neighborhood and community conditions as well as the structural drivers of risk and protective factors. Contextual evidence can be gathered through needs and assets assessments, census data, surveys, focus groups, and local administrative data (e.g., from hospitals, schools, and law enforcement agencies).

3. **EXPERIENTIAL EVIDENCE**[7] is the collection of knowledge and experiences of people who have practiced or lived in the community of interest, or have experienced the issue of interest firsthand and are able to connect to the realities, strengths, and challenges of the community. This evidence includes the experiences of those most impacted by inequities and is gathered through focus groups, interviews, co-designing projects, communities of practice, and community meetings.

OVERRELIANCE ON BEST AVAILABLE RESEARCH EVIDENCE

Traditional research methodologies such as RCTs have been considered the gold standard of evidence due to their use of rigorous methods in describing whether or not a program, policy, or process works.[3] While best available research evidence plays an important role in data-driven decision making, it is insufficient to understand and address the complexities of health and social inequities.

The public health field's overreliance on best available research evidence has contributed to biased decision making that reinforces structural inequities.[3] Traditional research methodologies that comprise best available research evidence present several challenges, which include harmful research practices, incomplete data, and exclusion of *historically marginalized groups.*[8]

Historically marginalized groups/ communities is used in this report to collectively refer to groups and communities that historically have experienced disinvestment and have been underserved — including Black, Indigenous, and other people of color (BIPOC); women; women of color; people with disabilities; people with low income; immigrants; people with limited English proficiency; and members of LGBTQIA+ communities.[9]

Excluding communities from the evidence base perpetuates underinvestment in these communities, compounding inequities in both data and resources.[2] Even when these groups are included in data collection and analysis, researchers often use broad categories (e.g., based on race and ethnicity) which may mask important differences and disparities within groups.[8] Consequently, individuals and communities most impacted by inequities are disproportionately excluded from decision making, exacerbating existing inequities in policies, programs, and practices.

Uplifting contextual and experiential evidence can help bridge the gaps, challenges, and the hierarchical privilege of best available research evidence as well as work towards the systemic advancement of **health equity and racial justice.** While organizations and agencies have put forth resources that are supportive of contextual and experiential evidence, most available guidance and tools are geared towards assessing best available research evidence for decision making (e.g. CDC's Understanding Evidence Part 1: Best Available Research Evidence[5]). This underscores the need for increased investment in contextual and experiential evidence, and preparing the public health field to weave and successfully integrate all three forms of evidence into decision making *(Figure 2).*[3]

Health equity is the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined by race/ethnicity, culture, class, national origin, or other means of stratification. Achieving health equity means that everyone has a fair and just opportunity to attain their full health potential and that no one is disadvantaged, excluded or dismissed from achieving this potential. Health equity requires the removal of systemic obstacles to health.

Racial justice would be attained if racial factors no longer served as robust and reliable predictors of key measures of health, safety, economic stability, or other important societal outcomes. Achieving racial justice means closing gaps between racially defined groups and engaging in processes that lead toward truth and reconciliation, justice, and fairness. This requires the elimination/reversal of the policies, practices, norms and messages that reinforce differential outcomes by race and a transformation of the systems and structures that uphold/reinforce persistent and widening inequities.

*Definitions from **Building Bridges: The Strategic Imperative for Advancing Health Equity and Racial Justice,** Prevention Institute.*[10]

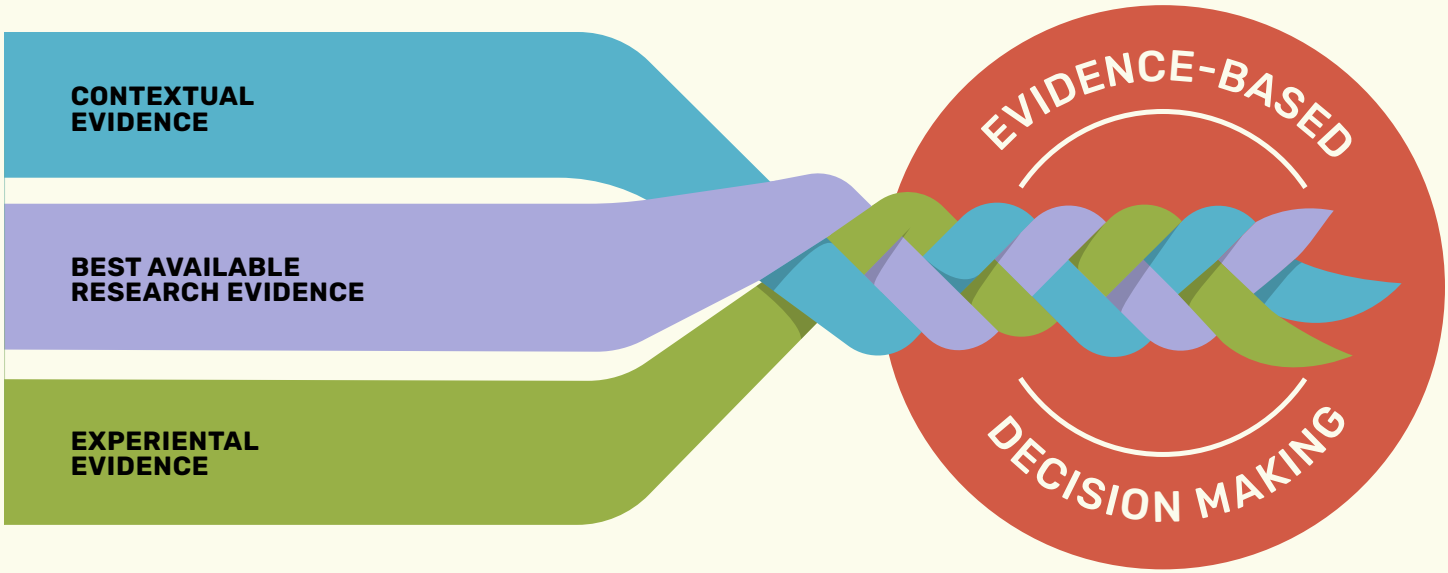


Figure 2. Reimaged A Framework for Thinking About Evidence that illustrates the importance of weaving all three forms of evidence for evidence-based decision making.

2 A SNAPSHOT OF THE CURRENT LANDSCAPE

To evaluate emerging opportunities and gaps in the public health field, Prevention Institute conducted a landscape scan analyzing how government institutions – including federal agencies, and state and local health departments – have worked with community groups and residents to create, uplift, and integrate contextual and experiential evidence as valuable and effective types of evidence in decision making.

The project team identified government agencies and community groups as the two main groups contributing to and benefitting from decision-making through the development, implementation, or evaluation of a policy, program, or practice. The main resource of this scan was HealthEquityGuide.org,[11] a Human Impact Partners (HIP) project exemplifying how health departments have advanced health equity within their departments, communities, and other government agencies.[12] In addition to the 30 case studies presented in the HIP project, we analyzed governmental, academic, and nonprofit resources and reports exploring the relationship between lived experience, racial justice, health equity, and types of evidence. The aforementioned case studies and reports – paired with conversations with eight field experts working in evaluation, academia, community-based organizations, and other public health sectors – identified frameworks, tools, approaches, and strategies featured in this report. Supported by scan results, this report will define key components and strategies for gathering, integrating, and sustaining contextual and experiential evidence.

3 KEY COMPONENTS OF UPLIFTING CONTEXTUAL AND EXPERIENTIAL EVIDENCE

The project team identified four key components of uplifting contextual and experiential evidence:

- **A** PRACTICING MEANINGFUL COMMUNITY ENGAGEMENT AND ELEVATING LIVED EXPERIENCE
- **B** SHIFTING POWER, OWNERSHIP, AND ACTION TO COMMUNITY
- **C** IMPLEMENTING COMMUNITY-DRIVEN METHODS AND APPROACHES
- **D** INVESTING FOR SUSTAINABILITY

Through additional research and engaging public health practitioners across the sector in the webinar series[13] for this project, we conceptualized how these four components are interrelated and support community leaders as they collect, integrate, and sustain contextual and experiential evidence, and ultimately weave all three forms of evidence to inform decision making *(Figure 3)*. Practicing meaningful community engagement and elevating lived experience; Shifting power, ownership, and action to community; and Implementing community-driven methods and approaches work in tandem with Investing for sustainability to strengthen the contextual and experiential evidence base through various strategies described in this report. The four components are critical ingredients and potential outcomes of uplifting contextual and experiential evidence.

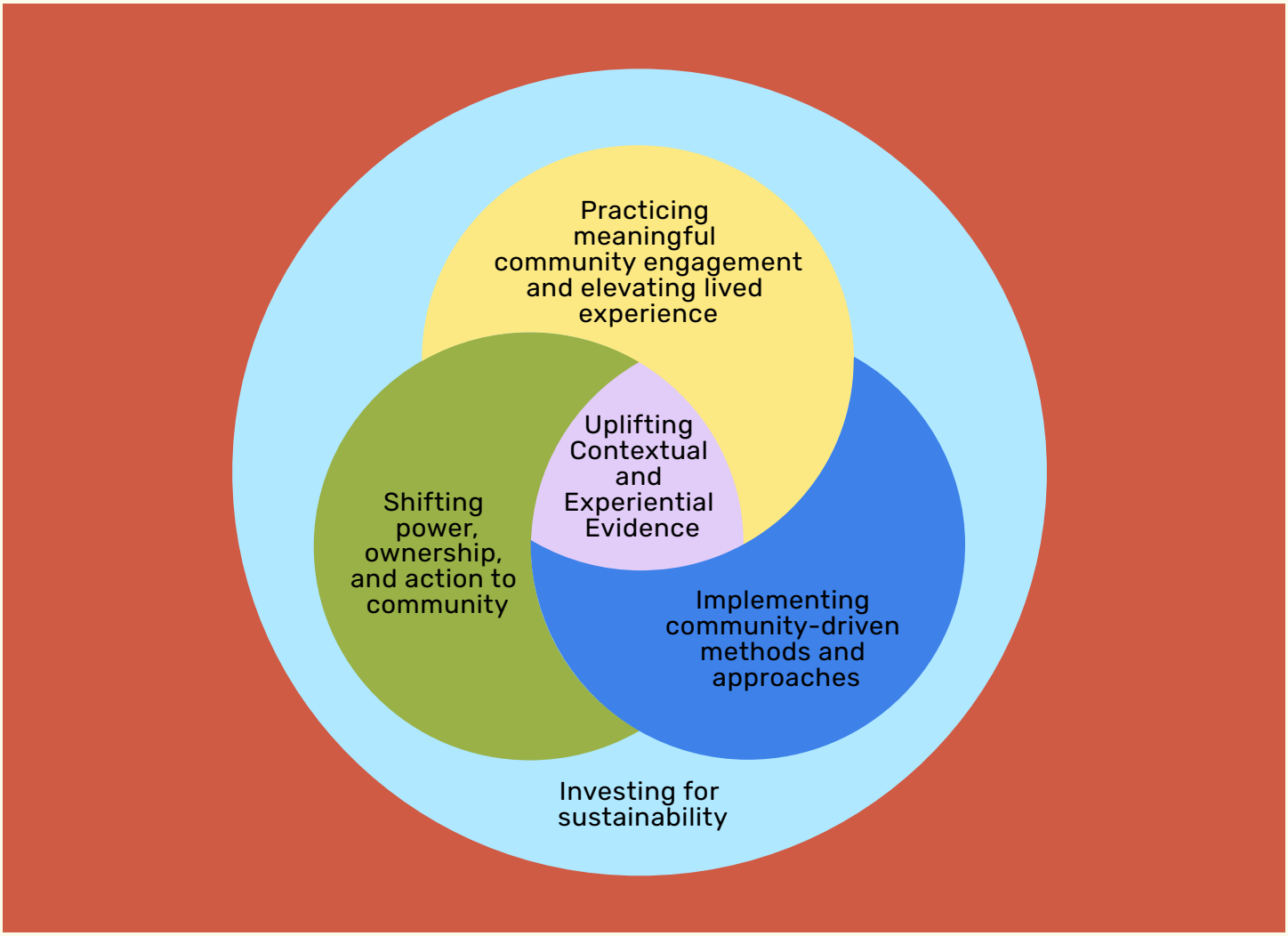


Figure 3. Four key components to uplift contextual and experiential evidence.

A PRACTICING MEANINGFUL COMMUNITY ENGAGEMENT AND ELEVATING LIVED EXPERIENCE

Meaningful community engagement is the foundation to generating and integrating contextual and experiential evidence into decision making. Meaningful engagement can look differently across communities and settings, and requires working with communities to understand (1) how, when, and to what extent community members want to be engaged and (2) the extent to which community members feel engaged.[14] Practicing meaningful engagement often involves sharing institutional decision-making power with community members and is rooted in shared values and interests.[15]

As part of a comprehensive community engagement approach, partnering with people with lived experience in the generation of evidence and decision making is essential to promoting equity and justice. People with lived experience are "those directly affected by social, health, public health, or other issues and the strategies that aim to address those issues."[16] While all community members and sectors play a role in health promotion, equitably engaging people with lived experience helps ensure that programs, policies, and research are responsive, accessible, and tailored to the needs and assets of groups most affected by public health issues and their solutions.

Meaningful engagement of community members enhances understanding of dynamic community contexts and nuanced experiences that may not otherwise be reflected in available research. Individuals and groups, including those with lived experience, can provide context to data, trends, and changes observed in their community, creating a comprehensive understanding of community conditions, needs, assets, and desires. Beyond contributing knowledge that is rooted in personal and community-level experiences, community members may also contribute professional and academic expertise on a given issue.

Considerations: Often, communities have little to no say in shaping research agendas. Institutions approach communities to conduct research that is of little benefit or practical relevance to those communities and leave, taking the community's data with them.[25] This extractive model of generating evidence in and on behalf of communities continues to cause harm, which explains the public's general distrust of academia and other power-holding institutions. Taking these harmful dynamics into consideration, building trust is especially necessary to integrate community expertise into evidence and decision making. Level of trust influences how community members engage with institutions, research, and evidence, and the decisions that impact them. Practicing meaningful community engagement can help build communities' trust in institutions.

Prioritizing community participation and leadership in institutional practices and decision making helps center the perspectives of groups that have been systematically excluded from engaging in practices such as:

- Setting agendas
- Identifying funding opportunities and priorities
- Developing strategic plans
- Driving research priorities and processes
- Designing, implementing, and evaluating programs and policies

Below, we list strategies and considerations for engaging community members, including people with lived experience, in producing evidence and decision making:

ENSURING ENGAGEMENT IS DIVERSE AND REFLECTS COMMUNITY OF FOCUS

Efforts to engage community members, including people with lived experience, must ensure diverse representation of the community of focus. To ensure accountability to equitable engagement, decision-makers should carefully define selection criteria for the population to be engaged and metrics to assess level of representation for an engagement. To do so, it is important to conduct outreach beyond "inner circle" colleagues, peers, and allies that are regularly engaged to broaden the scope of opinions, experiences, and expertise.

Considerations: While an individual's lived experience is valid and powerful, it is important to remember that a single individual's lived experience does not represent an entire community or system. Communities are not monolithic and the process for incorporating lived experience into the evidence base and decision-making processes must consider and reconcile varying, and at times conflicting, views and opinions.

BUILDING STRONG PARTNERSHIPS

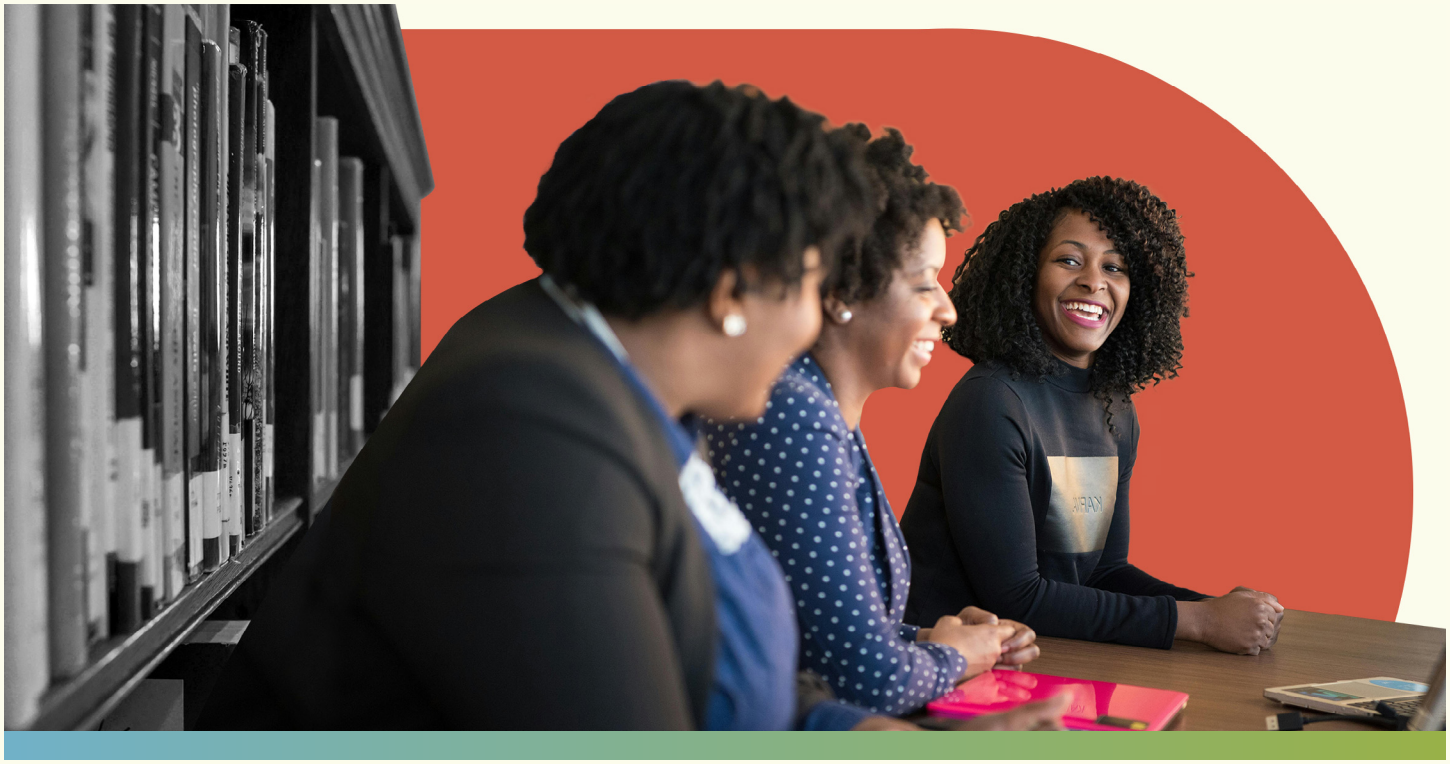
Strong community partnerships and relationships are the foundation to understanding the diversity of experiences, identities, and perspectives within a community, which in turn help identify appropriate outreach and engagement strategies. Strong partnerships are a cornerstone for building trusting relationships with community members and sustaining impact. Effective partnerships are characterized by mutual trust and respect, as well as defined goals, vision, and processes for accountability.

Example:

The National Black Public Defenders Association, BlackRoots Alliance (BA), the Cook County Public Defender (CCPD), and Northwestern University collaborated on a gun violence prevention and safety study summarized in the report Reimagining Public Safety: Community Listening Sessions with Black Communities and Public Defenders.[17] The study team held conversations with Black Chicagoans to understand community perceptions of public safety and public defenders. When the project launched in 2022, the partners spent the first two months defining the vision of the project, clarifying roles, and getting to know each other. A team of consultants from Northwestern University provided support in qualitative research. As the lead community recruiter and to boost community interest in the study, BA highlighted the benefits of participation and shared their mission of fighting for the safety and liberation of Black people. This messaging made community members feel that the project was genuine and supportive of their experience. BA also conducted multiple forms of outreach to recruit participants, meeting people where they were by canvassing door-to-door, attending community events, hosting Town Hall events in collaboration with churches, and holding meet and greets in city libraries.

The interviews were conducted mainly at churches and public library spaces, which are spaces that Black Chicagoans frequented and were comfortable for interviewees. When possible, a Cook County public defender would join interviews with a BA representative. Over the course of 103 interviews, community members shared how they define safety, their experiences with crime and the criminal justice system, and how they envision a dream future for themselves and Black communities.

The study forged strong partnerships that deepened BA's relationships in the community and provided opportunities for community members and Cook County public defenders to engage with one another.



Resources:

- Baltimore Lived Experience Advisory Committee:[18] Committee of individuals with lived experience who are shaping responses to homelessness in Baltimore City through advocacy, education, and recommendations to improve the quality of the homeless service system.

- Promoting Meaningful Partnerships with Lived Experience Experts:[19] Brief suggesting specific steps funders can take to support researchers in their efforts to meaningfully and ethically engage with individuals with lived experience.

- Strategies for National and State Groups to Equitably Identify People with Lived Experience:[20] Tool providing concrete strategies for identifying people with lived experience to engage in health and human services work.

- Recruiting Individuals with Lived Experience:[21] Guide highlighting questions to consider and discuss before recruiting individuals with lived experience to participate in a health and human services program or policy efforts.

- Methods and Emerging Strategies to Engage People with Lived Experience:[22] Based on a comprehensive environmental scan, key informant discussions, and consultations with lived experience experts, this brief identifies lessons learned for engaging individuals with lived experience to improve federal research, policy, and practice.

- A Guide to Community Engagement and Outreach for Community Groups:[23] Resource describing the community engagement process through examples and best practices.

- Why, What and How of Community Outreach and Engagement:[24] Resource describing how to engage local community members in decision making.

> ***When building relationships between community members and institutions, it is important to consider if the relationship is mutually beneficial and whether it is designed to be transformative (e.g., increases communities' skills and capacity to have more control over their data) or transactional and extractive (e.g., engages a few community members to check a box or to appease). Transformative relationships are often those that pave a path towards greater community power, ownership, and action.***

B SHIFTING POWER, OWNERSHIP, AND ACTION TO COMMUNITY

When generating evidence for decision making, institutions have an opportunity to exercise their power and authority at the service of communities by shifting power and ownership to communities.[26, 27] Greater community power and ownership contributes to a community's sense of belonging, agency, and capacity to change systems. In and of itself, community engagement does not constitute shifting power and ownership. Shifting power to communities requires an explicit commitment to widening the circle of people involved in decisions and in shaping evidence and strategies, especially people most impacted by inequities.[28] Institutions and communities collaborate through shared values and interests to support a community's influence and role in systems change.

A community's active involvement in generating evidence and decision making paves the way for greater community ownership, where communities have more direct control over decisions and resources needed to thrive.[27] The question of who owns data is of significant concern in valuing contextual and experiential evidence. Traditionally, researchers have asserted their authority as gatekeepers and owners of data, including data that reside in communities (for example, data on factors that affect a community's health). Uplifting contextual and experiential evidence demands community ownership of their data, which means that data collection, use, and sharing is controlled by the community from which it is gathered.[29] Community members should be able to maintain access to their data to further inform future decision-making efforts.[30] If community members involved in projects or improvement efforts can't access the data collected from their community, they will be forced to perform duplicative data collection or lack the data needed to make informed decisions. Investing in and supporting communities to manage, collect, and share their data promotes self-determination and allows communities to build local capacity and sustain their efforts over a long period of time.[27]

The strategies below illustrate various ways of shifting power and ownership in evidence and decision making to drive the community actions that are necessary to shape the conditions for equity.

SUPPORTING TRAINING AND CAPACITY BUILDING

Institutions, such as local and state health departments and universities, can shift power and ownership by:

1. Equipping residents and community members with the tools to produce and use multiple forms of data, lead strategies, make changes in their community, and build up additional resident leaders.

2. Building their internal capacity to shift power and ownership to communities (e.g., through organizational policies and workforce development).

3. Participating in capacity building activities led by community members who may already possess valuable research skills and resources.

Training and capacity building is a multi-directional process where institutions embrace existing assets and resources in a community and use their power and authority to build communities' capacity to produce and use evidence. Uplifting contextual and experiential evidence is one way to enhance community members' leadership and skills, as well as build internal capacity as power-holding institutions. Supporting community members as leaders enhances their ability to to influence policies and practices, and supports them in sustaining these efforts beyond the lifecycle of a grant-funded project.

Example:

The Alameda County Public Health Department[31] in California worked alongside grassroots organizers, advocacy organizations, and government partners to build internal capacity to change policies and practices for housing equity and affordability. Through an internal "Public Health 101" training series and pursuing public avenues of health equity advocacy (e.g., public hearings, community meetings, and government gatherings), public health staff participated in workforce and leadership development activities with a specific focus on institutional change and shifting power to partners with less formal authority. Consequently, the department was able to understand "problem priorities" for housing identified by community groups, improve housing policies and practices, and bridge gaps between housing and health. By providing resources and raising awareness for residents, the department increased involvement and forward momentum towards policy changes identified by residents. This work is ongoing, with continued training and capacity building activities to support the movement towards affecting social determinants of health, like housing and immigration justice.

Resources:

1. Houston Health Department Community Capacity Building Pilot:[32] The Houston Health Department conducted trainings for community members to advocate for change in their communities.
2. Communities Rise:[33] The Communities Rise Cohort Program provided learning opportunities and coaching to non-profit organizations as they enhanced their capacity to support community members.

DEVELOPING COALITIONS AND BUILDING COMMUNITY POWER

Having a structure in place that promotes equitable and representative partner participation and leadership, like a multi-sectoral collaborative structure, has been shown to be a powerful foundation for shifting power back to communities. By building partnerships between community-based organizations, residents, and local governmental agencies, each entity will bring power and knowledge that can be leveraged for large-scale, transformative changes.

Example:

Cook County Department of Public Health[34] (CCDPH) in Illinois and local community groups joined together to create the Collaborative for Health Equity (CHE) Cook County, focused on various upstream health issues like cancer screening, obesity, and food justice. The collaborative raised awareness about health inequities in their community and built power in low-income communities of color to successfully organize several policy wins in economic justice and immigrants rights. CHE Cook County formed alliances with base-building organizations to support campaigns that create the living conditions necessary for good health. The collaborative established a strong connection with the CCDPH due to the department's emphasis on the importance of prioritizing community-based meetings in an effort to combat government distrust often experienced by historically marginalized communities. These efforts led to a bidirectional relationship between social justice organizations in the community and CHE and CCDPH on issues of economic and health justice. CHE further supported power building capacity by creating a channel for future partnership and engagement by supporting local organizations.

Example:

The Kansas City, Missouri Health Department (KCMOHD) developed a long-term partnership[35] with Communities Creating Opportunity (CCO), a faith-based community organizing group, to build capacity of health department staff, engage communities, and promote positive health outcomes. The partnership was an opportunity for the health department to leverage their data expertise and for CCO to convene residents to share their stories and support policy-level changes. To infuse accountability and transparency early on in their partnership, the organizations developed a Memorandum of Understanding (MOU) to define their joint objectives. A key outcome of the MOU was the co-location of CCO within the KCMOHD, which allowed them to provide training to new staff in each organization. As an example of shared leadership, the directors of KCMOHD and CCO participated in the governing bodies of the other's organization. The integration of faith-based community organizations sharing their lived experiences in the community was the foundation of this partnership, resulting in various local policy wins and measurable changes in social determinants of health.

Resources:

- Public Health Institute California Overdose Prevention Network (COPN):[36] COPN efforts include equipping groups and coalitions with tools to promote health equity, identify top priorities, and build partnerships.

- BUILD Health Challenge:[37] The BUILD Health Challenge funding collaborative promotes partnerships between community-based organizations, community residents, local health departments, and hospitals, health systems, and health plans.

- Health Equity Collective:[38] The Collective promotes community engagement for collective impact.

ASSEMBLING CONVENING BODIES TO MOBILIZE COMMUNITY EXPERTISE

Commissions, advisory boards, task forces, and workgroups are opportunities to convene diverse community members to share their expertise on an issue, initiative, policy, or project. Typically, community members have varying degrees of decision-making power based on how the group is structured. For example, community members may opt for collaborative decision making where everyone in a team or group, regardless of formal role, is involved in decisions. This approach has the potential to foster trust, creativity, innovation, and collective accountability.

Considerations: A commitment to shifting power and ownership to communities requires setting up tools and mechanisms for accountability, such as:

- Developing a memorandum of understanding with community-based organizations to define roles and responsibilities, and scope of partnership
- Establishing a community advisory committee or other convening body that outlines bylaws, roles and responsibilities, and decision-making processes

Example:

The Health Policy and Planning Program of the San Mateo County Health System in California established the Youth Commission,[39] an advisory commission to the San Mateo County Board of Supervisors with up to 25 members, ages 13-21, who meet bimonthly. The commission was formed in 1993 to build social capital, self-efficacy, and power within youth in the county to lead, educate, and advocate for policies and issues impacting youth. Members of the commission play instrumental roles in youth-focused research, policy, and programming for the county, and have a direct relationship to the Board of Supervisors. The commission hosted the San Mateo County Youth Conference, released two San Mateo County Adolescent Reports – which included their data analysis and policy recommendations – and youth from the commission have served on other San Mateo County boards and commissions.

Considerations: The Trauma Informed Care Taskforce Co-Chair in Baltimore, Maryland, Fareeha Waheed, shared in an interview that the taskforce – composed of youth, parents, service providers, and other partners – has been intentional in modeling a horizontal leadership structure. All members of the taskforce are involved in decision making and take on shared responsibility and leadership for task force initiatives. Taskforce Chairs used tools like the Community Engagement Continuum to ensure equitable decision-making processes, considered the importance of valuing and balancing upstream and downstream experiences, and regularly revisited the taskforce structure and leadership.

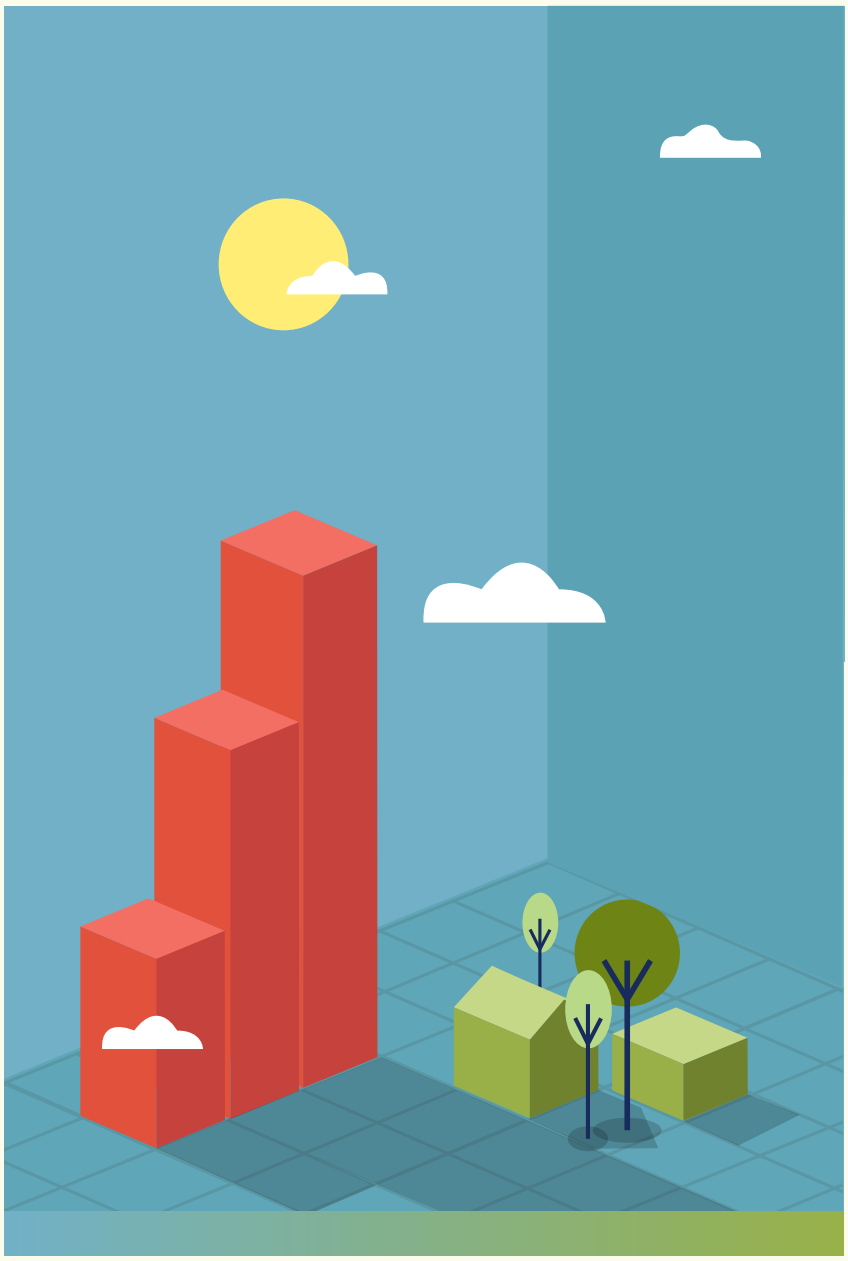
Resources:

- Tools and Resources for Project Based Community Advisory Boards:[40] Guidance from the Urban Institute that describes the implementation of community advisory boards.
- Youth Action Boards (YABs): Best Practices and Implementation Guidance for Youth Homelessness Demonstration Program Communities:[41] Describes how YABs are designed and implemented across the country.
- Indiana Youth Advisory Board:[42] In 2022, the Indiana Department of Health launched their youth advisory board, which aims to assess mental health, suicide prevention, and other public health initiatives and provide suggestions to enhance youth wellbeing in the state.
- Trauma-Informed Care Task Force:[43] First convened in 2021, Baltimore's Task Force intends to infuse trauma-informed care in services provided across the city. The Task Force includes city agency representatives and community members.

Shifting power and ownership lays the groundwork for community-driven data that meets local needs. Partners can leverage diverse tools and approaches to gathering this type of data.

C IMPLEMENTING COMMUNITY DATA METHODS AND APPROACHES

Evidence-based decision making requires the collection and use of measures related to health and wellbeing. Typically these come in the form of aggregated measures, like the number of program participants with a specific illness or condition, but different sources of data can be used to gather contextual evidence to provide a richer view of the factors surrounding the current health and wellbeing of a community. Community data, gathered through community-driven approaches and methodologies, can describe community characteristics (e.g., poverty, gender and/or racial economic inequities, and social norms) that go beyond individual-level data points to illustrate trends in the community.[44] When gathered and applied successfully, community data can broaden the types, scope, and breadth of evidence that is used in decision making. It produces data that is grounded in community context, illustrating a cohesive and nuanced picture of community assets and challenges.



Community data can fill in data gaps collected by institutions, and can be collected through various methods. It can be gathered and selected through secondary sources of data, like census or local administrative data, and through feedback or interviews with partners and community members to explore community-identified priorities and goals. Community indicators should be measurable and accurate, and can be sourced through existing databases or designed based on knowledge and context gathered with community members.[45] Indicators and measures are most useful when they reflect the language used within a community and create avenues for mutual understanding of shared progress.

Community data can also be aligned with experiential evidence and narratives gathered from the community, providing the context for perceived community issues or solutions and creating a more defined picture of the specific community. This data takes into account the specific historical context, trends, and cultural assets within a community that might impact how a program or intervention is implemented compared to a different community. Strategies and measurements that are grounded in lived experience better reflect the communities that will be impacted by the selected strategies.

The strategies below describe various ways of gathering community and local data to contribute to decision making.

UTILIZING RIGOROUS METHODOLOGY AND TOOLS

Decision-makers can use more than just surveys to understand community priorities and concerns, either through quantitative or qualitative means. Community-driven research approaches such as Community-Based Participatory Action Research (CBPAR) leverage quantitative and qualitative methods while engaging community members to produce contextual and experiential evidence for action.[46] It is important to note that not all frameworks or tools will be suitable for the community of focus. The selected approaches should be piloted with community members first to ensure they are aligned with community goals and preferences.

Example:

The Government Alliance on Race and Equity (GARE) Racial Equity Toolkit[47] utilizes a framework to identify clear goals, objectives and measurable outcomes when advancing equity and eliminating racial inequities. Guided by foundational questions, the Racial Equity Toolkit seeks to apply different types of data to understand impact of programs, practices, projects, and budgets; identify potential consequences of a decision; and develop mechanisms for successful implementation and evaluation. The Racial Equity Toolkit is most effective if used at all levels: government staff (providing the opportunity to integrate racial equity across all government functions), elected officials (ability to set priorities representative of their jurisdiction), and community-based organizations (ensure accountability of elected officials and government). With an explicit focus on methodology in data collection, analysis, and engagement, this report demonstrates how to collect and integrate community indicators with rigor to build long-term commitment and momentum to advance racial equity, including through long-term shifts in how decisions are made and movement towards healing and transformation.

Resources:

- Equity Indicators Tool:[48] Guidance from CUNY Institute for State and Local Governance on their Equity Indicators Tool.
- ACE Network:[49] This network brings together racially and ethnically diverse evaluators who have been historically underrepresented in the U.S. to access evaluation funding, professional development and community building activities, and connections to peers practicing Culturally Responsive and Equitable Evaluation.[50]
- Equitable Evaluation Initiative Framework:[51] Describes an innovative framework that challenges traditional evaluation methodologies through investigating axiology (what we determine to be right), ontology (what we believe to be true), and epistemology (what constitutes knowledge).
- Toward a Trust-Based Framework for Learning and Evaluation:[52] Resource that describes a trust-based approach to learning and evaluation in philanthropy.

ASSESSING LOCAL COMMUNITIES AND GEOGRAPHIC AREAS

To accurately describe the health or socioeconomic conditions where a program, policy, or practice will be implemented, grant-making organizations should use local data (e.g., at the county, city, or neighborhood levels). While important, global or national data may not be applicable to the community of focus. Secondary sources and information from partners, organizations, and residents can help assess what resources, assets, and needs are present in a specific community or geographic area. Incorporating multiple types of evidence into assessment will provide the best overview of the context and characteristics of the community, including what worked or did not work in the past and the specific priorities of residents in the community.

Example:

The Rhode Island Department of Health[53] worked with multi-sectoral partners and community groups and services to establish Health Equity Zones to improve health outcomes, reduce disparities, and improve environments of underserved communities. Each zone was tasked with developing local assessments and employing community asset mapping to establish baseline measures and assets of the community. The zones had great successes in relationship building, policy advocacy, and securing funding through highlighting place-centered strategies and data.

Resources:

- A Community Resilience Approach to Reducing Ethnic and Racial Disparities in Health:[54] The Toolkit for Health and Resilience in Vulnerable Environments (THRIVE) is a community assessment tool created by Prevention Institute to improve health outcomes and reduce disparities experienced by racial and ethnic groups who have been historically marginalized.

- Community Assessment to Understand Health Inequities among Farmworkers:[55] Southeast Arizona Area Health Education Center's Healthy Farms Program sought to address the structural barriers that local farm workers faced in accessing health care.

- Tower Health Community Health Needs Assessment:[56] Describes process for identifying and analyzing community health and social needs to plan and act upon unmet and prioritized needs.

BRIDGING NUMBERS AND NARRATIVES

Narrative data is qualitative information consisting of stories, quotes, and impressions that are gathered from community members, including residents, which describe the issues they see or solutions they want to pursue for a program, policy, or practice. The strategy of collecting narrative data allows researchers to create a multi-faceted view of data, where community context, like assets and history, from narratives can be combined with statistics and numeric values to provide a more robust view of the community factors and indicators that should be prioritized and measured.

Example:

Data Walks are a research tool that share and present data to community members and stakeholders to engage in a dialogue where community context and lived experiences are used to interpret and shape the data collectively. Urban Institute conducted a Data Walk[57] with the steering committee for the Promoting Adolescent Sexual Health and Safety project, which included residents, community leaders, local government officials, and representatives from community-based organizations. The researchers presented their survey results depicting the levels of substance abuse, risk behaviors, and victimization in the neighborhood related to sexual health and safety. After walking through the data, the steering committee shared their thoughts on how to make the survey more sensitive through language and terminology changes better reflecting the community, as well as questioning tentative conclusions and results where more data was needed. By giving the community members and partners an opportunity to own the analysis of the data, they were able to shape a narrative around the program that better reflected their community culture and context, which helped build a platform for advocacy.

Resources:

> **"DATA POINTS ARE TOPIC SENTENCES. STORIES HELP EXPLAIN WHAT IT MEANS."**
>
> **- Aristea Saulsbury,** McKinleyville Family Resource Center, Humboldt County, CA

- Do No Harm: Crafting Equitable Data Narratives:[58] A guide expanding the boundaries of what is considered an equitable data narrative.
- Health Equity Narratives: Content Testing & Strategy Validation:[59] Research on health equity narratives and how they move audiences.
- National Public Health Institute Transforming the Narrative Toolkit:[60] Toolkit that offers resources to support the creation of sustainable and cross-sector relationships, insight from partners who have amplified transformative narratives in their communities, and guidance on the development of justice-rooted language.
- Using the Promotora (Community Health Worker) Model to Engage, Empower, and Organize Patients for Positive Community Outcomes:[61] Stories from Clínica Romero's Community Organizing Department, which has maintained their mission of engaging, capacitating, and empowering patients to become health advocates for their community.
- County Health Rankings and Roadmaps: Narratives for Health:[62] Guide for shifting and building power and promoting health equity through narrative.

Gathering and utilizing community data, alongside community engagement and shifting power to communities, create the ideal conditions for the production and integration of contextual and experiential evidence for decision making. However, all of these efforts require financial and other forms of investment in order to be sustainable.

D INVESTING IN SUSTAINABILITY

Commitment to long-term investment for sustaining the collection and integration of contextual and experiential evidence is imperative to weaving multiple forms of evidence. Grant-making organizations provide resources and funding for communities and organizations to pursue their program mission and goals. By providing a steady and flexible source of funding to prioritized communities, funders can empower organizations and resident leaders to take action and carry out strategies that uplift contextual and experiential evidence.[63] Beyond funding, investments in social capital and capacity building can enable underserved communities to pursue efforts to inform decision making at the local level.

Monetary Investment

- Operational funding and grants are an effective way grant-making organizations can support community initiatives by supporting their administrative and personnel needs, rather than just program outcomes. Through these funds, organizations can support hiring and training or invest in methodologies to effectively gather contextual and experiential evidence.
- Flexible funding that is unrestricted to specific outcomes also provides grantees autonomy to respond to community-identified priorities and research activities based on emerging evidence rather than just a specific budget item. These more flexible funding structures can be used by organizations for technical assistance or capacity building, helping to sustain their ability to continue their data collection strategies long-term by establishing standards of practice and measurement.

Non-monetary Investment

When institutions provide additional investments and resources other than funding, such as connections to other organizations or personnel, community-based organizations are able to develop and sustain strategies and programs that incorporate different types of evidence.

- Providing support for data collection or evaluation can allow for community-based organizations to build a foundation of evidence and results that they have ownership of. This evidence can be used to build community narratives,develop programs, or seek opportunities for more funding and resource investment within the community.
- Funders can further support underserved community-based organizations or initiatives by facilitating resource sharing and community building. By facilitating spaces for coalition building between grantee organizations, funders can help build social capital within communities by creating bridges between organizations.[64] These connections can be leveraged for further network development, peer learning, and collaboration based on shared missions and goals, establishing a strong structure for sustainability.

Example:

Healthy Places NC[65] is a long-term program funded by the Kate B. Reynolds Charitable Trust that invested $100 million in under-resourced rural communities in North Carolina. The goal of this program included empowering community members to take action, increasing their capacity to solve and identify community issues, and making shifts in community norms and culture to promote better health outcomes. As the program progressed, the Trust evolved to investing directly into grassroots organizations to enable them to take action and promote equitable decision making at the local level. Specifically, they provided a technical team and access to a network of decision-makers and influencers who focused on helping grantees shift power dynamics, develop community champions and leaders, and connect with other organizations and funders.

This investment of funding, capacity, and resources enabled grassroots leaders to identify and prioritize local systems change efforts and civic engagement, resulting in notable accomplishments like published toolkits and resources for other organizations, improved and expanded programming, and participation in strategy development and decision making with power-holding networks. After their funding period ended, grantees indicated a notable shift in community norms and power dynamics in their communities, demonstrating how direct, long-term funding strategies can be used to build strong momentum for systems change efforts and other opportunities for underserved community-based organizations.

Resources:

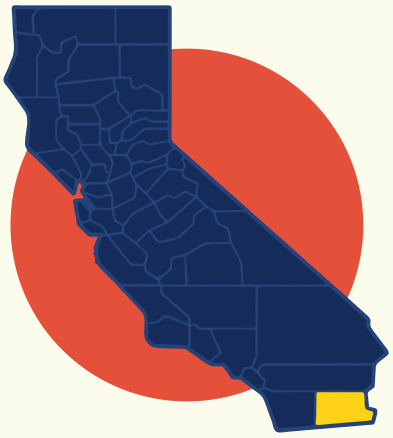
- Health Policy and Planning Program, San Mateo County Health System:[66] The County created the Community Implementation Fund to provide ongoing annual funding for primary prevention and health equity efforts as well as resources and technical assistance.

- Community Ownership: Emerging Models and Roles for Philanthropy, Kresge Foundation:[67] Report that describes several models for resource sharing and investment in communities.

4 WEAVING CONTEXTUAL AND EXPERIENTIAL EVIDENCE IN ACTION:

THE IMPERIAL COUNTY COMMUNITY AIR MONITORING PROJECT

The strategies and examples highlighted in the previous sections are snapshots of a larger picture: the weaving of multiple forms of evidence to inform decision making. The Imperial County Community Air Monitoring Project exemplifies the power of supporting community members in harnessing their expertise to produce locally-relevant data and make decisions for the wellbeing of their community. Below, we describe the project and visually highlight the ways in which it illustrates the components and strategies described in this report.



Background

Imperial County is nestled in California's Southeastern desert region and is home to a predominantly Latino and Spanish-speaking population. The county has cultivated a long history of agricultural production, one that generates half of all winter vegetables in the U.S. The county also houses a range of renewable resources such as wind, solar, and geothermal power. However, the combination of heavy agricultural and industrial activity, the negative impacts of the drying Salton Sea, and high vehicle pollution have contributed to poor air quality. An example of environmental racism, the county's poor air quality contributes to negative health outcomes among Latino families with low incomes and their children. As a county with one of the highest rates of asthma-related emergency visits and hospitalizations among children in California, community members identified air quality as a priority health issue.

Imperial County Community Air Monitoring Project

Limited by traditional air quality monitoring systems that did not provide neighborhood-level data they could use, residents voiced a need for local, real-time data on air quality to identify trends in air pollution and craft an action plan to reduce exposure to pollutants. In response to these needs, in 2013 the grassroots organization Comité Civico del Valle, California Environmental Health Tracking Program, University of Washington School of Public Health, and other academic partners came together to launch the **Imperial County Community Air Monitoring Project**[68, 69] with community residents. This project built upon a long standing partnership between Comité Civico del Valle and the California Environmental Health Tracking Program, a partnership between the California Department of Public Health and the Public Health Institute.

BUILDING STRONG PARTNERSHIPS

Community-led action

In this 5-year project, community residents were actively involved in the planning and implementation of an air monitoring network. The 40 air monitors that make up the network are located throughout the county and collect air quality data on a daily basis. The air quality measurements are publicly available on the network's website.[70]

UTILIZING RIGOROUS METHODOLOGY & TOOLS

SUPPORTING TRAINING AND CAPACITY BUILDING

Using a citizen science approach where community members participate in scientific decisions, the project trained community members on the science of air pollution and air monitoring, and

ASSEMBLING CONVENING BODIES TO MOBILIZE COMMUNITY EXPERTISE

interpreting and using data for action. The project also created a Community Steering Committee (CSC) of local advocates and residents, including youth, to ensure the project was guided by local knowledge, experience, and priorities. For example, through facilitated discussions, the CSC:

- Discussed factors that contribute to poor health in the county
- Examined health and environmental data for the county

ENSURING ENGAGEMENT IS DIVERSE AND REFLECTS COMMUNITY OF FOCUS

The CSC identified 11 priority communities where the first set of 20 air monitors were placed and over 40 residents from these communities identified potential air monitor sites. The CSC also provided valuable input to share data generated by the air monitors with the public in an accessible manner. The project team also included a Technical Advisory Group consisting of local, state, and federal agencies and universities who provided guidance on technical activities.

Below are notable impacts of the project, which underscore the importance of community-led evidence:

ASSESSING LOCAL COMMUNITIES AND GEOGRAPHIC AREAS

- After the implementation of the project, an investigation revealed that the local community monitors reported high pollution spikes that were almost double what the state monitors reported in the same time frame. This suggests that the state likely missed and underreported high pollution events in the county.[71]
- As part of the Air Quality School Flag Program, schools use the network's data daily to prevent students from being exposed to dangerous levels of air pollution.

INVESTING IN SUSTAINABILITY

- To ensure the sustainability of the project beyond the funding period, the Comité continued to own and operate the network, which involved staff training in data management and partner collaboration to explore additional funding streams that could support the network.[72]
- The project served as a model for the development of California's statewide Community Air Protection Program.

Takeaways

Weaving neighborhood-level data, residents' lived experience and expertise, and available research on air quality and monitoring produced local evidence and action for a pervasive health equity issue. Meaningful engagement of community residents most affected by the issue led to the creation of useful and accessible data for the community, increased community ownership, technical expertise, and capacity to advocate for improved policies related to air quality, and produced research that was responsive to community priorities.

5 RECOMMENDATIONS

Different sectors in the public health field -- federal agencies, local and state health institutions, community-based organizations, academic researchers, and philanthropy -- play multiple roles in realizing this goal due to their organizational power and privilege, and resources *(Figure 4).*

FEDERAL HEALTH AGENCIES	Federal health agencies (e.g. Health Resources and Services Administration [HRSA], Substance Abuse and Mental Health Services Administration [SAMHSA], CDC, etc.) fund a majority of local public health initiatives, influencing decisions about what programs are funded and how much funding is directly given to communities.
LOCAL AND STATE HEALTH INSTITUTIONS	Local and state health institutions (e.g. health departments) play an important role in funding many public health initiatives, helping set the priorities of a state or locality. These institutions can build deep partnerships and relationships with community-based organizations.
PHILANTHROPY	Philanthropy has unique flexibility and openness to funding a variety of innovations and strategies. Foundations can leverage their power and ample resources to support community- rooted efforts.
ACADEMIC RESEARCHERS	Academic researchers play a key role in generating evidence for public health. They have authority over how and what types of research is supported, upheld, and deemed credible
COMMUNITY-BASED ORGANIZATIONS	Community-based organizations have the greatest proximity to community residents and can organize opportunities to engage communities to uplift community data.

Figure 4. Key roles for each public health sector

While anyone can use the strategies in this report, the recommendations below outline actions that these five public health sectors can take to uplift contextual and experiential evidence and weave all three forms of evidence. Although the table below identifies the public health sectors that are well-positioned to act on specific recommendations, all sectors can play a role in the implementation of the listed recommendations. These recommendations supplement the components and strategies presented in this report.

FEDERAL HEALTH AGENCIES	LOCAL AND STATE HEALTH INSTITUTIONS	PHILANTHROPY	ACADEMIC RESEARCHERS	COMMUNITY-BASED ORGANIZATIONS

SECTORS	RECOMMENDATIONS
	Encourage presenting **multiple forms of evidence**, including contextual and experiential, in developing and responding to **funding opportunities, grant reporting, and evaluation.**
	Create **accessible funding opportunities** for community-based organizations, and provide flexible timelines and ample budget to meaningfully engage community members*.
	Release **guidance to operationalize contextual and experiential evidence**, as has been done with best available research evidence.
	Develop **internal policies and procedures** to ensure agencies and institutions are **directly engaging with people with lived experience.**
	Conduct an **internal review of types of evidence collected** by the agency/institution to assess the forms of evidence they currently use and to ensure that multiple forms of evidence are supported and upheld.
	Build **long-term partnerships and trust with community-based organizations and residents** to strategically collect and utilize all three forms of evidence.
	Create **opportunities to share power** with community residents and organizations to be part of decision-making bodies.
	Employ **methodologies that integrate contextual and experiential evidence** (e.g. community-based participatory research, etc.).
	Employ, train, and co-design research and projects with **community researchers.**
	Meaningfully engage community residents and organizations to **create and prioritize research agendas.**
	Practice and support **community ownership in data governance.**
	Commit to **sharing stories and narratives of the community** members and residents engaged in programs, policies, and practices.
	Collect **administrative, quantitative, and/or qualitative data on priorities** that are elevated by community members.
	Build **relationships with academic researchers** trusted by community-based organizations and members.**
	Recognize the **organization's convening power** and **invite institutional partners** to the decision-making table.

* Recommendation based on CLASP's Redefining Evidence-Based Practices: Expanding our View of Evidence[2]

** Recommendation based on work led by the Black and Brown Collective[73]

CONCLUSION

Evidence-based decision making has become a cornerstone of public health programs, policies, and practices. While recommendations to use different types of evidence have been put forth by the CDC, the overreliance on best available research evidence has overshadowed the importance of exploring and using other forms of evidence that rely on community expertise. The components and strategies outlined in this report provide various avenues to collecting, integrating, and sustaining contextual and experiential evidence, and how different actors in public health can use their power and authority to weave all three forms of evidence into decision making. By embracing community knowledge in institutional practices, bodies, relationships, and policies, the public health field can be better equipped to generate timely, informed, and relevant solutions to the structural and systemic challenges facing communities.

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