A roadmap for effective community engagement in healthcare

Final report from INSPIRE Phase I

July 2024

inspire

community engagement for better healthcare

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Organizations

Camden Coalition

Community Catalyst

cacp the center to advance consumer partnership

PFCCpartners Patient & Family Centered Care

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE® Transforming health care through partnerships

People with lived experience


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Executive summary

INSPIRE (Initiating National Strategies for Partnership, Inclusion, and Real Engagement) is a collaborative and coordinated team of organizations and people with lived experience committed to advancing the practice of authentic community engagement in the U.S. healthcare system.

INSPIRE's Core Team currently includes the Camden Coalition, Community Catalyst, the Center to Advance Consumer Partnership, PFCCpartners, the Institute for Patient-and Family-Centered Care, and six experts with lived experience: Burt Pusch, Carlos Benavides, LaRae Cantley, Rebecca Esparza, Savina Makalena, and Stephanie Burdick.

Background and definitions

Community engagement (CE) is a powerful tool that can build trust, advance health equity, create cost-savings and efficiencies for healthcare organizations, and lead to healthy and thriving communities. While healthcare organizations are increasingly interested in undertaking CE, implementation of meaningful CE activities remains limited and highly variable. These implementation challenges often prevent CE initiatives from achieving desired goals like improved access, quality, cost, patient experience, and community well-being.

To create a shared understanding of CE within healthcare, the INSPIRE team crafted this definition:

> "Community engagement is the different ways in which healthcare organizations can reach out to, engage, and partner with people with lived experience (PWLE), with the goal of working together to improve healthcare and achieve positive health outcomes."

Our definition intentionally emphasizes community engagement as work that centers engagement and partnership with people with lived experience (i.e. people who reside in a shared geographic area and/or who share common aspects of identity or experiences). CE is distinct from concepts such as 'patient activation,' 'partnerships between organizations,' and 'health education and promotion activities' that are often conflated with CE.

The purpose of INSPIRE is to bridge the gap between interest in CE and implementation. This report presents actionable recommendations for both healthcare organizations and community members to implement more and better community engagement.

Beginning in May 2023, the INSPIRE team engaged over 300 people from across the U.S. (including healthcare professionals and people with lived experience) in extensive research activities — including a field survey, key informant interviews, a series of listening sessions, and a literature analysis — in order to assess the current state of CE in the U.S. healthcare system and identify a set of recommendations for how healthcare organizations, funders, and community members can advance these efforts.

The INSPIRE team developed a framework for what makes community engagement meaningful (or not), described in our brief, The nine dimensions of authentic community engagement.

The brief provides concrete practices to support adoption of the framework into action.

Key findings on the current state of CE in the US healthcare

1

Healthcare organizations express a high degree of interest in CE, but implementation remains variable and limited.

Major implementation gaps include:

- viewing CE as partnerships with other organizations rather than partnerships with PWLE;
- transactional, one-time engagement with PWLE;
- lack of respect for "lived expertise;"
- inconsistent organizational structure and culture to support CE; and
- a lack of diverse and equitable participation – particularly from communities most impacted by structural racism and injustice and health disparities.

2

How organizations and communities approach CE makes a big difference to both the process and outcomes of the work.

There are many CE promising practices that the field can learn from and build upon, including:

- centering equity and acknowledging power dynamics;
- engaging PWLE early and often in a variety of ways; and
- providing PWLE fair and equitable compensation.

3

Those undertaking authentic CE find much value in the work at an individual, organizational, and community level.

Both healthcare professionals and PWLE report that authentic CE can:

- address health disparities and advance health equity;
- lead to more effective and efficient allocation of resources;
- create improved patient experience, trust, and community perception;
- foster a sense of personal fulfillment and being able to "pay it forward" to help others; and
- help to build social connection/ connectiveness and foster well-being.

4

Structural and policy factors impact the adoption of authentic CE.

There are several opportunities to address structural factors such as incentives, policy requirements, and sustainable funding models to support CE. It is vital that these changes are developed in partnership with PWLE and sufficiently resourced.

Recommendations

1

Strengthen the practice and impact of community engagement initiatives by increasing access to training and learning communities for healthcare professionals leading the work.

There is enormous opportunity to advance CE by expanding access to hands-on training and technical assistance that meets frontline professionals where they are by providing not only conceptual frameworks, but also step-by step guides to real-life applications of CE promising practices, including adapting approaches to meet the specifics of their own community and organizational context.

2

Prioritize leadership development and capacity building for PWLE – particularly those from under-represented communities – to step into partnership roles.

While there is much work for healthcare organizations to foster authentic, inclusive, and accessible contexts for CE, PWLE desire better access to mentorship and peer learning opportunities to equip them with the skills and knowledge to effectively engage with healthcare organizations as equal partners. PWLE co-leading these capacity building efforts is essential to addressing current gaps in diversity, equity and inclusion and to building genuine community power through CE.

3

Improve organizational-level infrastructure to support high-quality and impactful community engagement.

For CE initiatives and those leading the work to be successful, organizations must adopt supportive systems, policies, and frameworks that enable CE work to flourish. To support organizations in doing so, it is vital to define the roles and responsibilities of those carrying out CE work and develop a shared approach to CE impact measurement - specifically one that can help address the central barrier of resource constraints by supporting a business case for CE.

4

Address structural and policy opportunities that could improve the uptake of community engagement.

Advancing federal and state policy requirements for CE and exploring a set of healthcare CE accreditation standards — either as a standalone program or as a component of an existing accreditation program like health equity — would have significant impact on ensuring that CE is being adopted in meaningful and sustainable ways. Crafting and implementing these approaches in partnership with PWLE, prioritizing incentives rather than penalties to address the need to properly resource CE work, and including support structures to ensure high-quality implementation will ensure these approaches achieve their desired outcomes.

Recommendations by role

Role of healthcare executive leaders

- Embed community engagement as an ongoing organizational strategy to ensure the policies, programs and processes meet the needs of those being served
- Create leadership accountabilities to ensure CE is integrated across departments, service lines, quality improvement and SDoH initiates
- Invest the necessary resources to position CE for meaningful and sustained impact including staff, training, compensation for those with lived expertise and workforce roles such as peer specialists and community health workers

Role of healthcare professionals leading community engagement work

- Adopt practices centered on achieving authentic and sustained CE
- Relentlessly measure the impact of CE — both processes and outcomes
- Drive cross functional accountabilities for inclusion of CE as a core organizational practice
- Build from existing organizational and community relationships with PWLE before creating something new

Role of funders (philanthropists and grant-makers)

- Embed clear and measurable expectations around engagement with PWLE into all grant making activities
- Make sustainable investments that provide ongoing and flexible resources to support grantees in achieving meaningful community engagement, including fair and equitable compensation to those with lived expertise
- Act as influencers to ensure the value of community engagement is integrated into reimbursement structures, performance measurement systems and other systems of healthcare accountability

Role of people with lived experience

- Call attention to the role and contributions of people with lived experience in advancing goals shared by community and healthcare organizations
- Share perspectives and experiences around gaps in diversity and barriers to engagement along with ideas to help organizations design CE approaches that overcome these challenges
- Help organizations identify existing community groups and community-led initiatives to connect with and support
- Using the INSPIRE frameworks and language, insist on transparent communication from organizations around CE goals, strategies, compensation policies, and sharing of outcomes

Conclusion

We are at an important moment of opportunity for community engagement. High interest across healthcare in undertaking CE is beginning to be translated into action, but there is much work left to do. The findings and recommendations in this report provide a roadmap for how healthcare organizations and people with lived experience across the U.S. can realize the full potential of authentic CE to build trust, advance health equity, create cost-savings and efficiencies for healthcare organizations, and create healthy and thriving communities.

Image description: Community members engage in conversation at a community health event.

SECTION 1

INSPIRE background

INSPIRE (Initiating National Strategies for Partnership, Inclusion, and Real Engagement) is a collaborative and coordinated team of organizations and people with lived experience committed to advancing the practice of authentic community engagement (CE) in the U.S. healthcare system.

INSPIRE's Core Team currently includes the Camden Coalition, Community Catalyst, the Center to Advance Consumer Partnership, PFCCpartners, the Institute for Patient-and Family-Centered Care, and six experts with lived experience: Burt Pusch, Carlos Benavides, LaRae Cantley, Rebecca Esparza, Savina Makalena, and Stephanie Burdick. It was important to the INSPIRE team that our project's process and structure reflected our values of meaningfully including people with lived experience in a variety of ways throughout the project, including as equal members of the Core Team. The members of the Core Team with lived experience each brought a variety of first-hand lived experiences navigating healthcare systems as patients/consumers and/or family caregivers as well as ample experience working in partnership with healthcare organizations as Patient/Family Advisors (PFAs), advocates, and/or community leaders.

At the outset of our work together, the INSPIRE team started with the hypothesis that *despite the trend in healthcare (and other sectors) of increased interest in CE, a significant gap exists for organizations to understand how to actually build and sustain meaningful partnerships with community members and people with lived experience (PWLE).*

When done well, CE is a powerful tool that can build trust, advance health equity, create cost-savings and efficiencies for healthcare organizations, and lead to healthy and thriving communities. Through our individual and collective work in the field, INSPIRE partners observed significant gaps in practices, processes, and workflows that support meaningful partnerships, as well as in the policy and financial structures that are necessary to incentivize, sustain, and broaden adoption of this work. These implementation challenges often prevent CE initiatives from achieving desired goals like improved access, quality, cost, patient experience, and community well-being.

This report documents the findings of the first phase of our work. Beginning in May 2023, INSPIRE undertook extensive research and strategic planning activities – including a field survey, key informant interviews, a series of listening sessions, and a literature analysis – in order to assess the current state of CE in the U.S. healthcare system and to identify a set of recommendations for how healthcare organizations, funders, and community members can better advance these efforts.

Across these activities we engaged over 300 people (including healthcare professionals and people with lived experience) from across the U.S. and identified several important strategic areas of opportunity for strengthening authentic CE. In addition to our research and data collection activities INSPIRE also worked with a social impact consultant, Illustra Impact, to complete a Strengthens/Weaknesses/ Opportunities/ Threats (SWOT) analysis to learn more about the experience and perspective of each organizational and individual partner and assess the team's capabilities for carrying our recommendations from the work. We also worked with an implementation science consultant, EQUIPA, to identify strategies and approaches that will support translation of our recommendations into meaningful and tangible improvements in CE practice within healthcare.

Who is this report for and how should you use it?

One of the most exciting and most challenging aspects of CE is that the work is relevant to so many stakeholders in our healthcare system – from frontline healthcare providers to health system leaders, to payers, to policy makers, to community-based organizations – and of course, community members and PWLE. It is no easy task defining an audience for this work.

At the end of this report, the "Role-specific recommendations" section lays out specific calls-to-action for the following groups:

- Healthcare executive leaders
- Healthcare professionals leading community engagement work
- Funders (philanthropists and grant-makers)
- People with lived experience (PWLE)
- Policymakers
- Community-based organizations (CBOs)

In addition to reviewing the specific recommendations that relate to your professional or personal context, we encourage all readers to consider the following questions as they read through this report:

1. To what extent does this information align with or differ from my own experiences and perceptions of CE?
2. How can I use the frameworks and language in this report to advance a shared understanding of what CE is (and is not) in conversations that I am a part of?
3. How can I use the findings and recommendations in this report to strengthen my approach to advancing authentic CE – in whatever role I am in?

Image description: A diverse group of Patient Family Advisors sit around a conference table having a discussion.

Definitions

Early in our work, we realized that a central challenge is that there is no commonly-held definition across healthcare of who we are referring to as "community" or what we mean by "community engagement." In response, INSPIRE developed our own set of definitions for these terms and authored this blog post to begin the conversation about the need for shared language: Are we speaking the same language? Defining what we mean by "community engagement" – Camden Coalition (camdenhealth.org)

Who is "community"?

Community can refer to people who live in the same geographic area and/or people who have characteristics or experiences in common (i.e., "people with lived experience"). It is also common for healthcare organizations to conceptualize their community as the other organizations and agencies who share their geographic or service population focus. This includes community-based organizations (CBOs), federally qualified health centers, governmental agencies, and even other medical practices.

What is "community engagement"?

The INSPIRE project crafted this definition of CE:

> "Community engagement is the different ways in which healthcare organizations can reach out to, engage, and partner with people with lived experience, with the goal of working together to improve healthcare and achieve positive health outcomes."

Like the definitions of CE from World Health Organization and U.S. Centers for Disease Control and Prevention, our definition intentionally highlights concepts of relationships, collaboration, and outcomes and prioritizes plain language that is accessible across different audiences. Importantly, our definition centers work with PWLE themselves, as opposed to working with other organizations. This distinction is intentional and important to our team's belief that CE is truly about those with lived experience.

While organizational partnerships have many benefits, they are not synonymous with individual-level engagement that brings PWLE directly into communication and partnership with healthcare organizations. Not all organizations are equally representative of the experiences, goals, wants, needs, and priorities of people who live within a community. Some organizations are authentically community-rooted and led by PWLE and others are not. While healthcare organizations build partnerships with other health and social care organizations for many reasons – such as service coordination, social-need referrals, and/or as a strategy for building connections with people in the community — organizational-level engagement on its own is not a substitute for directly involving PWLE.

Academic literature discussing engagement frequently references terms such as "patient activation" and "patient and family engagement," but in practice this is often referring to engaging individuals in their personal healthcare such as self-management of health conditions and shared decision making, not in organizational/system level initiatives working towards broader community health outcomes.

Despite the similar terminology, the goals and activities of patient activation are distinct from CE because patient activation typically lacks a communal aspect, is often strictly medicalized or medically centered in its goals, and typically does not connect to community-level improvements in health outcomes. It is worth noting that there can be synergistic elements between CE and patient activation. While healthcare providers may prioritize patient activation at the point of care, system-level transformation through CE is key to sustaining and spreading patient activation practices.

While the focus of the INSPIRE project is on advancing partnerships between healthcare organizations and PWLE, we do not mean to suggest that organizational partnerships or patient activation are not worthy and beneficial endeavors – they certainly are. Rather, our project has limited its scope to partnerships between healthcare organizations and PWLE because there is much opportunity to strengthen this work to advance some of the most pressing goals – shared by healthcare stakeholders and community – of advancing health equity, creating cost-savings and efficiencies for healthcare organizations, and fostering healthy and thriving communities.

CE is not:

- **Patient activation** that focuses on engaging individuals in their own care and management of health conditions
- **Partnerships between organizations** where different healthcare, governmental and/or community-based organizations/agencies coordinate to improve service provision.
- **Health education and promotion activities** that focus on brining health-related information into community settings

While these activities are all worthy and beneficial endeavors, they are distinct from the practice of CE – that centers engagement and partnership with people with lived experience to lead to organizational, systems, and population-level improvements.

What activities does CE include?

Community engagement encompasses a wide variety of activities and approaches. In the late 1990s, the International Association for Public Participation developed the Public Participation Spectrum to categorize and describe the different ways that public entities can involve citizens in the decision-making process. There are now multiple "spectrum" models describing different CE activities and levels of participation including:

- VCCC Alliance's Model of Consumer Engagement
- Facilitating Power's Spectrum of Community Engagement to Ownership

These models lay out different approaches and activities ranging from low levels of community involvement (e.g., "informing" or "consulting") to high levels of community involvement (e.g., "collaborative" or "community ownership").

CE activities across the spectrum can be applied as a strategy across different levels of healthcare from care delivery to organizational design to governance and policymaking. At the organizational level, this can look like PWLE partnering with organizational leaders and providers to determine how care is planned, implemented, and evaluated; participating in quality improvement initiatives; or advising on facility location or design. Organizations can work with PWLE on targeted, specific initiatives (e.g., a project working group) and/or create standing bodies such as patient-family advisory committees (PFAC) whose members contribute to an array of projects and initiatives.

The spectrum framework is useful for healthcare professionals leading community engagement work to consider different models for engagement and partnership. While there are benefits to ensuring that CE opportunities include deeper engagement approaches towards the right side of the spectrums, such as "partnership" and "community ownership," it is also important to understand that these higher levels of engagement require higher levels of time, resources, and commitment from organizations and from PWLE. Creating CE initiatives that span across the spectrum can create opportunities for more people to engage in the ways, times, and amounts that meet their interests and abilities, and PWLE themselves should have a say in how engagement/partnership opportunities are constructed as well as in which ways they would like to be involved.

Image source: vcccalliance.org.au/

Creating CE initiatives that span across the spectrum can create opportunities for more people to engage in the ways, times, and amounts that meet their interests and abilities.

What makes CE "good"?

Once we agree on who community is and what community engagement looks like, it is important to define what makes community engagement meaningful/authentic, or not. Through a series of facilitated conversations, our Core Team identified nine dimensions of authentic community engagement which we shared and validated during project listening sessions.

A few examples of successful CE case studies:

State Examples of Medicaid Community Engagement Strategies: *Two Case Studies*

shvs.org

Engaging Communities of Color to Promote Health Equity: *Five Lessons from New York-Based Health Care Organizations*

chcs.org

Spotlight on Member Engagement and Elevating the Consumer Voice

azahcccs.gov

Lessons in Centering Community

fullframeinitiative.org

For community engagement to be authentic it should be:

1. **Asset-based**
2. **Diverse & inclusive**
3. **Equitable**
4. **Impactful**
5. **Integrated**
6. **Mutually beneficial**
7. **Resourced & compensated**
8. **Transformational & restorative**
9. **Trust-based**

We discuss these dimensions – and practices to bring them to life – in further detail in this brief:

The nine dimensions of authentic community engagement

Historical and social context of community engagement

Describing the historical and social context of CE is challenging, in part due to the lack of shared definitions and the various applications for CE across different sectors (e.g., healthcare, higher education, public policy, etc.). According to the authors of *Building Sustainable Communities: The Impact of Engagement*, "CE has occurred throughout history, long before the term 'community engagement' existed. The concept became widely popular in the 1960s-1970s, during the civic engagement movement, when individuals were encouraged to actively engage with their communities and promote democracy by expanding citizen participation in problem solving and broadening access to social and political capital. Whereas decision making, and 'solving' societal issues had previously been understood as a government responsibility, it became more common for government to interact with the public in terms of informing and even consulting with community members on issues that affect them."

It's important to note that CE often has a slightly different orientation than advocacy and community organizing because CE centers those that currently control power and resources (public agencies and institutions, healthcare organizations, etc.) as the conveners and initiators of engagement and partnership, whereas community organizing and advocacy often center community members themselves as the initiators — often working from outside of existing systems of power rather than alongside them. This orientation may conflict with commonly articulated goals of authentic power sharing and community power building because it places existing power structures at the center of change making.

Certainly, community organizing and community-led change making has deep and wide roots in the U.S. The civil rights movement, disability rights movement, and mental health consumer movement are all important 20th century examples. Present day approaches to CE can benefit from embracing this historical context of community-driven change making by remembering that communities are capable of conceiving and carrying out efforts to improve their circumstances apart from sanctioned activities and opportunities that those in power may create for them.

Image description: A Black woman and older Black man, both smiling, dance together at a community BBQ.

SECTION 2

INSPIRE activities and methods

The INSPIRE Core Team formed several sub-teams to focus on carrying out Phase I activities. Each sub-team was composed of members from across INSPIRE's organizational partners and PWLE on the Core Team. Below is an overview of the methods of each research sub-team. Additional details on sub-team activities and findings are contained in the final summary reports linked in "Supplemental Materials".

Listening sessions

INSPIRE's Listening Session sub-team was led by staff of the Camden Coalition and Community Catalyst, along with Burt Pusch, Savina Makalena, and Carlos Benavides. The team worked collaboratively to identify appropriate forums and goals for each listening session, to develop discussion guides, and to facilitate the sessions.

In-person sessions were held at major healthcare-focused conferences. The INSPIRE team either applied to hold a session or were invited through their connection with conference organizers. The sessions were promoted through conference materials and/or conference attendees were invited via email. Participation in all sessions for conference attendees was voluntary and uncompensated. Attendee counts were derived from paper sign-in sheets made available to session attendees and are likely slight undercounts of participation acknowledging that not everyone completed their sign-in.

A virtual session was conducted exclusively for people with lived experience, as PWLE were overall underrepresented at the listening sessions held at healthcare conferences. We recruited PWLE through the networks of INSPIRE team partners. In recognition that PWLE are most often participating as individuals and not as an extension of a paid professional role, session attendees were offered a $50 gift card in return for their participation.

In each session, an INSPIRE team member took detailed notes. The notes were then reviewed and discussed by the team to surface major themes and takeaways from each session. Finally, the team met to discuss overarching themes and takeaways from the full series of sessions and objectives which are presented below.

In addition to holding listening sessions, at American Hospital Association Accelerating Health Equity conference and the Putting Care at the Center conference, we also hosted a table-top crowd-sourcing activity. We asked conference attendees who visited our table to write responses on stickers to one or more of the following questions and place them on our "community engagement rose bush" poster:

- On a rose sticker, please share: What is going well with your community engagement/partnership work?
- On a thorn sticker, please share: What is the biggest challenge you face with community engagement/partnership work?
- On a watering can sticker, please share: What would help your community engagement/partnership work grow?

Across the two conferences we received over 47 responses to these questions which we subsequently categorized by theme and included in our analysis of outcomes from our listening sessions.

Image description: A poster board designed to look like a rose bush, used for the INSPIRE crowd-sourcing activity

Listening session #1

FORUM/LOCATION: American Hospital Association Accelerating Health Equity conference, May 16-18, 2023

ATTENDEES: 21 (primarily healthcare professionals)

Session objectives

- Validate the goals and approach of the INSPIRE project
- Understand what attendees see as major bright spots and major limitations for the current state of community engagement in healthcare
- Understand attendee perceptions for how INSPIRE can best prioritize our research efforts
- Understand attendee perceptions for how INSPIRE can best communicate and disseminate findings

Listening session #2

FORUM/LOCATION: Virtual session held over Zoom on Oct 20, 2023

ATTENDEES: 14 (exclusively PWLE)

Session objectives

- Share/collect feedback/validate our value proposition for PWLE
- Understand perspectives on most impactful ways for CE initiatives to be accessible and inclusive
- Identify what our project can do/create to best meet the needs of PWLE
- Identify helpful pathways for dissemination – where do people get their info from?

Listening sessions #3-4

FORUM/LOCATION: 2023 Putting Care at the Center conference, Nov 1-3, 2023

ATTENDEES: 51 across two sessions (mix of healthcare professionals and PWLE)

Session objectives

- Identify intrinsic and extrinsic motivators for this work.
- Understand the most compelling ways to talk about value (ROI) from the perspective of PWLE and healthcare professionals
- Understand how work is currently being funded and supported, and how sustainable these streams/strategies are.
- Identify how INSPIRE can best support efforts to advance community engagement? What resources, tools, and support are needed?
- Understand PWLE and healthcare professionals' perspectives and opinions about what constitutes the "ideal future state" of CE In healthcare (less significant objective)

Listening session #5

FORUM/LOCATION: Institute for Healthcare Improvement Forum, Dec 10-13, 2023

ATTENDEES: 5 (primarily healthcare professionals)

Session objectives

- Understand to what extent CE is currently seen/understood/used as a QI strategy
- Identify the most impactful opportunities to advance CE as a QI strategy and the current barriers to doing so.
- Identify how INSPIRE can best support efforts to advance community engagement (in QI initiatives?). What resources, tools, and supports are needed?

Literature analysis

INSPIRE's Literature Analysis sub-team was led by Community Catalyst. The targeted literature analysis emerged from a thematic analysis from the first INSPIRE listening session with healthcare administrators held at the American Hospital Association's Accelerating Health Equity conference. The targeted literature analysis was iterative and allowed for feedback loops with the Listening Sessions and Key Informant Interview Teams and was divided into project phases to allow for collaboration and feedback with other sub-teams.

We chose to use the term "targeted literature analysis" to reiterate that this review is targeted towards the specific goals of the INSPIRE project, as opposed to a more comprehensive academic viewpoint. This terminology allowed us to hone our focus to the core questions of the INSPIRE project and prioritize literature most relevant to our goals.

The targeted literature analysis utilized a variety of databases, including EBSCO Discovery Service, PubMed, JSTOR, HHS (Health and Human Services) Public Access, Wiley Online Library, Sage Journals, ScienceDirect, and Google Scholar. In addition to these peer-reviewed sources, the analysis included reputable "grey literature" sources. Examples of other publications and sources include the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services; National Academy of Medicine; Milbank Memorial Fund; American Institutes for Research; Urban Institute; Center for the Study of Social Policy; California Health Care Foundation; Institute for Medicaid Innovation; Center for Health Care Strategies; and the National Academy for State Health Policy.

Key informant interviews

INSPIRE's Key Informant Interviews (KII) sub-team was led by the Institute for Patient-and Family-Centered Care, PFCCpartners, Camden Coalition, Savina Makalena, Burt Pusch, and Stephanie Burdick.

The KII team conducted 21 virtual interviews — nine with PWLE and 12 with healthcare professionals.

We recruited PWLE through the networks of INSPIRE team partners. We developed a survey asking PWLE to provide demographic information and information about their healthcare experiences. The KII team reviewed survey responses and collaboratively identified potential interview participants, prioritizing diversity in race, gender, and geography. A member of the KII team who is also a PWLE contacted selected individuals to schedule interviews and answer any questions that potential participants had about the project.

The process for recruiting healthcare and community partners began by working with the INSPIRE core team to identify perspectives of interest. These included:

- National organizations (e.g., policymakers, funders, associations)
- Healthcare systems and organizations with varying levels of community engagement expertise and experiences
- Public health organizations
- Community-based and community-led organizations

Within these categories, we identified potential participants based on team member suggestions and sent email invitations along with an overview of the INSPIRE project. As needed based on non-response, we identified alternate participants.

Inclusion criteria:

- **Publications:** Peer-reviewed academic articles, reports, studies, and literature reviews from reputable sources. Include non-peer-reviewed publications from reputable sources, such as government agencies, reputable research institutes, recognized industry organizations, or established healthcare foundations.
- **Content:** Literature that directly addresses community engagement in healthcare, including frameworks, strategies, best practices, unique needs populations, outcomes, tools, and toolkits. Conference abstracts, dissertations, theses, book chapters, and other non-primary sources can also be included depending on relevance.
- **Relevance:** Literature that specifically focuses on the impact of community engagement on health equity, successful interventions and models, reimbursement models (e.g., pay for performance, bundled payments, ACO shared savings programs, social impact bonds), promising strategies, policy and legislation, perspectives and experiences of key stakeholders, and gaps in the existing literature.
- **Date range:** Include literature published within the past 10 years to ensure relevance and currency. For literature published between 5-10 years ago, inclusion will be determined by relevance, equity, and language choices.
- **Alignment with existing frameworks:** Assess whether non-peer-reviewed publications align with established frameworks or conceptual models related to health equity and community engagement, such as the social determinants of health framework or community-based participatory research principles.
- **Equity focus:** Give priority to non-peer-reviewed publications that explicitly address issues of health equity, health disparities, or social determinants of health within the context of community engagement in healthcare. Look for approaches that prioritize inclusive community engagement and demonstrate an understanding of structural determinants of health.
- **Diverse perspectives:** Seek non-peer-reviewed publications that incorporate diverse perspectives, including those of marginalized communities, underserved populations, or individuals with lived experiences of health disparities. This can help ensure that equity considerations are adequately represented.

Exclusion criteria:

- **Irrelevant content:** Exclude literature that does not directly address community engagement in healthcare or is not related to the specified goals and objectives.
- **Duplicate sources:** Exclude duplicate publications or multiple versions of the same study.
- **Outdated literature:** Exclude literature published before the specified date range to focus on recent research and advancements.
- **Non-healthcare focus:** Exclude literature that primarily focuses on non-healthcare-related community engagement (e.g., community engagement in education, social services).
- **Focus outside of the U.S.:** Exclude literature that primarily focuses on healthcare system outside of the United States.

Please see our literature analysis for a complete list of search terms used.

The KII team developed a semi-structured interview protocol to guide interviews. Interview topics included:

- **Experiences with community engagement:** Roles, contributions, specific partnership initiatives.
- **Value proposition:** Motivation for partnering and engaging, value proposition for engagement, funding for work, payment or reimbursement models that enable community engagement.
- **Promising structures, practices, processes, and workflows:** Processes and practices that promote meaningful, equitable, and impactful engagement; how organizations can make PWLE feel welcomed and respected; how organizations can foster diversity, equity, and inclusion in engagement.
- **Impact and outcomes:** How "successful" engagement is defined; how contributions from PWLE are incorporated; how results of efforts are communicated to PWLE; changes made as a result of contributions from PWLE.
- **Challenges and barriers:** Barriers to meaningful engagement, ways in which challenges have been addressed.
- **Opportunities and priorities for INSPIRE:** How the INSPIRE project can help advance community engagement and create sustainable change, pathways to stronger partnerships, and priorities for implementation support.

All interviews were scheduled to be one hour in length and were conducted virtually over Zoom at times convenient for participants. While we had the ability to provide translation if needed (Spanish and ASL), this was not requested by any of the participants. One PWLE participant used a speech-to-text assistive communication device. All participants were offered a $100 incentive for participation.

All interviews were audio-recorded and Otter.ai was used to prepare initial transcripts. Team members then reviewed, edited, and de-identified final transcripts. To analyze transcripts, we used a collaborative process consisting of the following steps:

- **Step 1: Create analysis pairs.** We created four analysis pairs consisting of one PWLE on the INSPIRE core team and one KII team member.
- **Step 2: Review transcripts.** Each analysis pair was assigned between 5 and 7 transcripts to read through and review.
- **Step 3: Complete analysis template.** One individual in the analysis pair was assigned as the primary analyst, with responsibility for completing an analysis template that captured key learnings by category (i.e., value of community engagement; effective practices, ideas, and innovations; challenges and barriers; and ways to share INSPIRE learnings and engage PWLE). The template also provided space to capture quotes that were particularly impactful along with analyst impressions, insights, and questions. Once the primary analyst completed the template, the secondary analyst reviewed it and provided edits and additions. Within each analysis pair, individuals alternated the roles of primary and secondary reviewers.
- **Step 4: Develop KII themes.** A senior staff member (i.e., lead analyst) reviewed all completed templates, capturing key findings and grouping them into themes. The lead analyst developed two documents: one to summarize themes from KIIs conducted with PWLE, and one summarizing themes from healthcare professionals' interviews.
- **Step 5: Review and verify KII themes.** The lead analyst shared the PWLE and healthcare professionals' summaries with all analyst pairs to ensure the validity of themes based on their review of transcripts.

Field survey

The INSPIRE survey team was led by the Center to Advance Consumer Partnership, Camden Coalition, and Stephanie Burdick. The team co-designed a custom survey that was fielded in November 2023 through a snowball convenience sampling technique that started with the posting of a QR code link to the instrument at the Camden Coalition's *Putting Care at the Center* conference held in Boston on November 1-3, 2023. The survey was shared by INSPIRE's team members through their networks and organizational communication channels.

The objective of the survey was to collect input from people who work in healthcare organizations to explore key questions regarding current practices of community engagement including:

- How is community engagement achieved in healthcare settings?
- Which approaches have been most successful?
- Why and how do organizations incorporate community engagement into business strategies?
- What barriers and challenges do organizations face in effectively engaging the individuals and communities they serve?
- What messages about the value of community engagement best resonate with healthcare professionals leading community engagement work?

Over the course of a month, 175 responses were received with 141 responses considered complete in that the respondent answered more than one question.

Image description: Several community members engage with a presentation at a health fair by raising their hands

INSPIRE process for inclusion of PWLE

From the project's conception, the INSPIRE team has been committed to authentic inclusion of PWLE as equal partners in the work and has created a variety of opportunities for PWLE to participate and contribute. Below we highlight some of approaches to CE within INSPIRE's process that have been most successful:

We included PWLE from the earliest stages of the project by sharing our draft concept note for Phase I work with PWLE we had established relationships with, and intentionally left space for the team to respond to the insights and directions of PWLE as the project unfolded.

We created a balanced number of seats on the project Core Team for people with lived experience (6) as for organizational partners (5).

We created a variety of ways for PWLE to participate in and contribute to the project including:

- Representatives on the Core Team including participation across research sub-teams
  - We encouraged all Core Team members – organizational partners and PWLE to self-select what sub-teams they participated on based on their interest, skillsets, and capacity. Each sub-team created a variety of ways for people to participate ranging from co-creating and carrying out work to consulting/reviewing.
- Participation in listening sessions and KII
- Receiving updates about INSPIRE's work via email listservs and information sessions
- Offering individual meetings to connect with people who had interest in learning more about the project and/or contributing

We provided flexibility in participation by encouraging a culture of "step up, step back" for people to be involved however and how often they were able to. We recorded meetings, shared detailed meeting notes, and offered individual touchpoints if people missed meetings and needed to get back up to speed.

To recruit participants for various activities we sent an email out to a few of the INSPIRE organizational partners' networks of PWLE and included a simple online "interest form" asking for contact information, demographic data, and why and how people wanted to be a part of the project.

- Within two weeks of circulating the form through only select networks, we received well over a hundred responses – indicating widespread interest from PWLE to participate in CE related projects.
- Responses to the form helped us offer participation opportunities based on people's interests and with consideration of diversity factors including race, gender identity, age, geography, disability status, etc.

We provided equitable and flexible compensation to PWLE who served on the Core Team and those who contributed through listening sessions and KII.

- Compensation rates were based on suggested amounts from the Fair Market Calculator - National Health Council.
- As needed, we worked individually with PWLE to create payment plans that would not interfere with eligibility for public benefits they were receiving.
- In addition to financial compensation, we also covered costs for Core Team members with lived experience to attend and participate in professional conferences.
  - We paid directly for travel and accommodation expenses upfront rather than expecting individuals to pay out-of-pocket and wait to be reimbursed.

We invested resources into providing training and skills building opportunities open to all Core Team members.

We endeavored to recognize and address power imbalances that exist between Core Team members participating in a professional capacity and those participating as PWLE by:

- Trying to avoid jargon and acronyms and defining terms when something was unclear.
- Directly acknowledging instances when organizational representatives and PWLE had different project roles or expectations (e.g., fundraising and funder relations) and making space for PWLE to participate in activities they were interested in even if not part of their specific scope of responsibilities.
- Acknowledging that several INSPIRE Core Team members had both relevant lived and professional experiences and creating space for those wearing multiple hats to draw from both skillsets (e.g., a member of an organizational partner who is also a PWLE led KIIs with PWLE).

Limitations

While the INSPIRE team went to lengths to ensure robust data collection drawing from a diverse set of experiences, we acknowledge some important limitations in our approach. First, there is likely selection bias as participation in our research activities is not a representative sample of all healthcare organizations or all PWLE – it is skewed towards people and organizations that are already interested and/or engaged in CE. Those who are wholly unaware of or disinterested in CE are unlikely to have participated in voluntary research activities on the topic.

Secondly, although we made every effort to encourage candor from participants in our research activities, there is likely self-report bias as healthcare organizations feel there is social desirability in commitment to CE and may have over-emphasized their activities or impact.

Finally, the lack of shared language for community and community engagement that was discussed earlier in this report presented a challenge for our work. While we went to lengths to define these terms to ensure research participants understood that the focus of this project is partnerships between healthcare organizations and PWLE, it is possible that despite this, some people spoke to other types of work sometimes conflated with CE such as partnerships between healthcare organizations, community health initiatives, patient activation, or PWLE advocating for their own personal care/services.

Image description: A member of the INSPIRE team adds sticky-notes to a poster during a team activity

SECTION 3

Major findings

1

Significant interest, inconsistent implementation

Overwhelmingly across our research, healthcare professionals expressed a personal and organizational commitment to community engagement. Healthcare organizations and their staff see CE as "the right thing to do" and an important way to build trust, improve health outcomes, and advance health equity.

In our field survey, when asked if CE was a strategic priority for their organization, 82% of respondents who work in healthcare organizations replied "yes" or "somewhat yes." Some reasons that healthcare organizations are committed to CE include:

- Understanding the business value to the organization including
  - Assuring organizational strategic plan and goals are aligned with the needs of the community
  - More efficient allocation of resources – limited resources focused on what matters most
  - Achieving improved care, service, outcomes, and health equity for consumers
  - To gain a competitive advantage, differentiation, fiscal strength, and grow market share – by creating a strong connection to community champions for the organization
- Seeing CE as integral to the organization's mission
- Requirements by regulators and/or funders

Despite high interest, our research also shows that implementation of meaningful CE remains highly variable across the U.S. healthcare system and many initiatives fall short of what can be considered "authentic engagement."

1.1 Viewing CE as partnerships with other organizations rather than partnerships with PWLE

One important limitation is that lack of a common definition for CE means that healthcare organizations are often approaching the key activities and desired outcomes differently. We found that it is more common that healthcare organizations think of "community engagement" as building partnerships with other organizations serving the same geographic community and/or undertaking community health education/promotion and less often think of it as engaging and partnering directly with people with lived experience.

Some healthcare organizations strategically partner with community-based organizations that they view as closer to community members themselves and therefore better able to represent their perspectives and/or help recruit PWLE for direct participation in CE. In these instances, community organizations have done significant work to build trusting relationships with communities and populations, and their reputation as a "credible messenger" is critical to their success. Partnerships that do not reflect authentic engagement or benefit the community can damage the credibility of the community-based organization.

1.2 Transactional, one-time engagement

When healthcare organizations are engaging directly with PWLE, this engagement is often limited to low-impact and transactional activities like surveys and one-time focus groups. Responses from the INSPIRE field survey showed that while healthcare professionals report that surveying community members is the most common form of CE being undertaken at their organization, they also feel it is among the least effective approaches:

> "Effectively gathering diverse information from the communities we serve is optimized when we seek feedback following actual change implementation. Relying solely on surveys isn't sufficient; it's crucial to focus on understanding the impact of these changes. Yet, the follow-up after implementation is often neglected despite its immense significance."
>
> *– Survey respondent*

Both healthcare professionals and PWLE feel that too often organizations are engaging people late in their decision-making process and are being brought in as a final step to "sign-off" on something that had already been decided. Too often, CE initiatives fail to respond to or acknowledge feedback and requests from the community and struggle to connect community input to tangible opportunities for change.

1.3 Lack of respect for "lived expertise"

Across our research, PWLE consistently expressed that they often felt a lack of respect when participating in CE work with healthcare organizations which manifests in several ways, including: limited roles/time dedicated for PWLE to contribute, non-verbal cues from professionals indicating dismissal of what someone said or disapproval of how they said it, and not dedicating time at the start of meetings to provide necessary background, context, or glossaries of terms/acronyms to ensure PWLE can participate on equal footing in a group of majority healthcare professionals. This can be isolating for community members and discourage PWLE from sharing their truths, experiences, and perspectives.

In several KIIs, PWLE indicated a lack of understanding about the burdens placed on PWLE when they are asked to "give their time, their treasure, and their trauma" and emphasized that PWLE are often put in vulnerable situations associated with sharing their stories without appropriate support and respect from healthcare organizations.

1.4 Inconsistent organizational structure

Our research shows that there is little consistency in if/how organizations define and structure the role of staff carrying out CE responsibilities and if/how activities are coordinated across different departments and teams within an organization. For many healthcare professionals, CE is a secondary responsibility to their primary job functions, and activities related to engaging directly with PWLE, patients, and community members are often spread across organizational teams including marketing, health equity, community health, patient services, etc. without a unified or coordinated strategy to ensure alignment towards overarching goals for CE.

1.5 Lack of diverse and equitable participation

Finally, a gap noted by both healthcare professionals and PWLE in our research is the lack of diverse and equitable representation of people with intersectional identities or from communities impacted by structural racism and other social/political/economic injustices in most community engagement work.

Healthcare professionals often referred to this in terms of populations and communities that were "hard to engage," while people with lived experience often referred to this in terms of the need for organizations to overcome barriers for people to participate.

One KII participant explicitly stated that without a specific equity lens to engage those who have been marginalized, community engagement may unintentionally contribute to ways in which people are excluded or oppressed. Participants further noted that even groups that are doing CE "well" are often engaging only the most vocal community leaders and members, who may not be fully representative of the diversity of patients served.

2

The multi- dimensional value case of community engagement

Despite our finding that the state of CE in healthcare is often characterized by variable and limited practices, our research also confirms that there are many community engagement bright-spots and that those undertaking what our team calls "authentic community engagement" find much value in the work at an individual, organizational, and community level. There is even some meaningful overlap between how healthcare professionals and community members describe the value they find in participating in CE.

2.1 Addressing health disparities, advancing health equity

First, both healthcare professionals and PWLE find that CE is an important step in advancing equitable health outcomes. CE is unique in how it allows health systems to examine the root causes of inequities through its ability to shift power towards historically marginalized communities. This helps health systems better understand the impact of racial bias, discrimination, and structural racism on communities in ways they could not without the active voice of the community (Allen et al., 2021; Parsons et al., 2021).

Engaging communities most marginalized by health systems, such as communities of color, to repair these disparities creates more equitable systems builds a better system of care for everyone (NORC at the University of Chicago, 2021).

2.2 Effective and efficient allocation of resources

Healthcare organizations also find CE to be a valuable tool to be more effective and efficient in their allocation of resources and approaches to improve outcomes across the healthcare triple aim of access, quality, and costs.

> "When the community is engaged, there are fewer needs to be met on limited resources. The community has vast knowledge of where and how needs are met and often step up to write about how they have met those needs in their own lives or care needs. It truly is the PWLE that make our organization powerful and drive the work we do." *– Survey respondent*

KII participants consistently noted that CE is vital to helping healthcare organizations understand community perspectives, gaps, and assets, and in listening sessions, many healthcare professionals referred indirectly to the opportunity cost of designing interventions without community input that then fail to achieve their desired outcomes.

2.3 Improved patient experience, trust, and community perception

In our literature analysis there is evidence that CE can improve patient experience as measured through the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. This is likely because PWLE have been engaged at an organizational and systems level in identifying and implementing processes and practices that benefit other patients like them.

Our literature analysis and responses from KII participants also found that CE can improve trust and community perception of organizations and lead to increased positivity within the organizational culture.

"I believe our organization realizes that we rely on the community's perception of us to be fiscally successful and to have a generally good reputation in the field. They understand that developing programs and policies without the input of a community can result in resentment from community members and lack of support from community members." – *Survey respondent*

2.4 Personal fulfillment and paying it forward

Across listening sessions and KIIs we heard that for PWLE, a major component of the value they derive from community engagement work is the opportunity to "pay it forward" by using lessons from their (often challenging) experiences to hopefully improve the experience of others. PWLE expressed a desire to be heard and valued for their experiences and to be of service in ways that lead to new ideas and changes in healthcare. Participants emphasized how important it was for PWLE to have input in developing or changing policies, processes, and practices that directly affect them For many PWLE, community engagement relates to the hope that conditions can be improved and that their work can contribute to bringing about positive changes for their community and people navigating health and social challenges similar to their lived experience.

"[CE] is the most poignant and meaningful thing I could possibly imagine coming into my life" – *KII participant, PWLE*

"[CE] is way for me to be a philanthropist without money." – *KII participant, PWLE*

2.5 Creating connection and fostering well-being

One common way healthcare professionals and PWLE find value in community engagement is through increased connectedness and well-being. For people with lived experience, involvement in community engagement includes socialization, network and relationship building, and feeling "plugged in" to work and issues impacting them, their families, and communities. For healthcare professionals, CE can provide an opportunity to focus on building relational and authentic connections with community members not restricted by the demands and time-constraints of clinical interactions.

Our literature analysis found that health system staff engaged in CE report increased staff morale and overall job satisfaction, pointing to more collaborative relationships between patient advisors and staff and reconnecting with the values that lead them to their careers originally through recentering care around people (Markus Hodin et al., 2019).

2.6 Limitations: Measurement and justifying the business case

Finally, there are two important challenges to note when discussing the perceived value of CE.

First, while healthcare professionals who have been directly involved with effective community engagement initiatives reflected that it's easy to "see and feel" the value when things are done well, many still struggle to justify and articulate the value of CE to healthcare executive leadership or to frame the value in the financial terms that are often a key consideration for those on the "business side" of healthcare.

"I don't know if the value has been demonstrated in such a way that it clicks with business professionals yet."

– *KII participant, healthcare professional*

Secondly, while CE literature includes a wide variety of metrics to understand effectiveness in CE evaluations, there is no widely accepted approach for measuring the impact of CE (Feeney et al., 2020; Oldfield et al., 2018). Impact measurement approaches – much like the context and activities of CE initiatives themselves – vary significantly. Notably, most measurement approaches do not include outcome measures, and focus largely on process measures such as:

- Community satisfaction with engagement process
- Diversity of opportunities available to PWLE
- Level of participation of PWLE
- Meaningful involvement of communities of color and representation of a diversity of lived experience
- Adequacy of resources
- Level of institutional awareness of CE
- Partnership dynamics and trust

3

Employing promising practices makes a difference

A central question explored across much of our research is what practices underlie authentic, meaningful CE initiatives. In addition to the nine-dimensions framework that the INSPIRE team created and validated through discussions at listening sessions in response to this question, our research also identified several important "promising practices" that support authentic CE.

3.1 Centering equity, acknowledging power dynamics

In meaningful CE models, equity is centered in all aspects – including both process and outcomes (Aguilar-Gaxiola et al., 2022; Parsons et al., 2021) — and PWLE have a significant role in helping define the success, effectiveness, and impact of a particular initiative (Aguilar-Gaxiola et al., 2022; Smith 2017).

CE models that genuinely represent the communities served by healthcare organizations foster trust, particularly with individuals and communities who have been historically marginalized and who have experienced structural inequities. These groups often have had harm done to them by the healthcare system, and the process of building trust at times requires direct acknowledgement and repair for these harms.

Successful CE efforts bring an awareness and acknowledgement of power dynamics between different participants, such as PWLE and hospital staff. Implementing CE on the right end of the engagement spectrum, which is characterized by shared decision-making and shared power/authority, is a process that often involves challenging existing structures and requires health systems to probe how they have held power, their internal culture, and how holding that power may have harmed PWLE (Carman et al., 2013; Parsons et al., 2021).

3.2 Engaging PWLE early and often

Healthcare organizations engaged in authentic CE guard against inauthentic or token engagement by identifying ongoing roles for PWLE that reflect shared leadership and engage the community in key decisions. For instance, PWLE partner in the design and implementation of interventions and continue to have a voice in how programs are run.

CE works best when there are diverse opportunities for PWLE to participate (across the engagement spectrum) and when CE initiatives are integrated throughout an organization, such as within direct care, organizational governance, and within the broader community. It is also aided by institutional transparency about engagement efforts and acknowledgement of missteps and challenges (Dworetzky et al., 2023; AIR, 2017).

> "We have found great success in engaging the people we serve in every level of program planning, design, and implementation. Our programs and services are designed in collaboration with everyone they will affect. That way, decisions are made which include the voices of all stakeholders and what matters most to each of them."
>
> *– Survey respondent*

In listening sessions, PWLE recommended that the three important steps that support transparent and trust-based relationships are to involve them early and often in the planning and decision-making process, to actively report back if and how their feedback was used, and for organizations to authentically recognize lived experience as a set of expertise needed to improve their work.

3.3 Fair and equitable compensation

In relation to infrastructure investment, nearly all KII participants with lived experience felt that providing compensation for PWLE was a significant part of establishing effective, equitable, and ongoing processes for partnership.

> "To have them [PWLE] valued and respected for their life journey in this way is just extremely important. You've got to not only tell people that they're respected but show them that they're respected through financial compensation." *– KII participant, healthcare professional*

Participants spoke about the need to create structures and policies for securing and managing funding while also highlighting challenges such as budgets that do not include funding for PWLE, institutional restrictions on how payment is provided, and the impact that payments may have on income-related benefits for PWLE.

The nine dimensions of authentic community engagement

1. **Asset-based**
2. **Diverse & inclusive**
3. **Equitable**
4. **Impactful**
5. **Integrated**
6. **Mutually beneficial**
7. **Resourced & compensated**
8. **Transformational & restorative**
9. **Trust-based**

Read the brief:

camdenhealth.org/resources/the-nine-dimensions-of-authentic-community-engagement

4

Structural and policy factors impact the adoption of authentic community engagement

Another key finding across our research was the impact of structural factors such as incentives, policy requirements, and sustainable funding models on the adoption and sustainability of CE.

4.1 Resources and reimbursement

When asked on our survey what an organization needs most to improve its use of CE, "more funding" was the most common response. Less than half of survey respondents reported that funding for CE activities came from the organization's overall or department budgets, with 36% relying on grants and 20% relying on other sources.

Multiple healthcare professionals across listening sessions and KIIs also noted the lack of funding, incentives, and capacity to support CE. Several participants described the constant search for funding as "frustrating" and "draining" for those working in CE. Even when funding is secured, there often is no way to sustain engagement when the funding ends.

> "[It feels like it is better to] not even start a program if it's not going to be sustainable – you can have all the right intentions, but if you cannot follow through, you will lose that community connection and trust."
>
> *-KII participant, healthcare professional*

Other factors that compound the lack of incentives and take away from the time and resources available for community engagement include limited health system accountability for community health goals, healthcare payer restrictions, staff shortages, and the existing burden on staff and clinicians. This challenge is felt not only by healthcare professionals but also by PWLE.

> "[CE] is not yet baked into a lot of the performance management and incentive regimens or accountability regimens within healthcare institutions. It's a nice to have, not a must-have…if you look at contracts, what's 'must have' is what's in writing; it's what you're paid to do or not. There's a big leap between the words and the actions here and the performance structures and the contracts for C-suite members."
>
> *-KII participant, healthcare professional*

> [CE] is an area that's incredibly understaffed, doesn't have enough people and they're overworked, and they're burned out… they're doing their level best. It's complicated." *-KII participant, PWLE*

4.2 Federal policy

Our literature analysis extensively explored federal community benefit legislation. "Community benefit" refers to nonprofit hospitals being given tax-exempt status due to their spending that contributes to community health (which is frequently in the form of free or reduced-cost care to low-income patients).

The Affordable Care Act (ACA) created new requirements that sought to shift community benefit spending toward community health improvement, which only accounted for 5% of hospital community benefit spending in 2009 (Young et al., 2013). As part of this federal law, non-profit hospitals must now conduct community health needs assessment (CHNAs) every three years, which — at least in theory — provides an important opportunity for CE. In reality, new community benefit requirements have led to limited increases in meaningful CE.

Our literature review found that about half of hospitals studied worked with community partners for CHNA implementation, and even when CE is taking place, it is often limited to passive engagement strategies, such focus groups with PWLE or PWLE helping to collect data (Cramer et al., 2017; Petiwala et al., 2021). In practice, there are few opportunities for PWLE to actively influence the CHNA data collection process, the interpretation of the data, or activities aimed at addressing identified community needs moving forward.

Community benefit categories that most impact communities and lead to CE represent only a small fraction of spending. Only 4% of community benefit spending goes towards community health improvement services and only 1% towards community building, while 45% of CHNA spending per capita comprises of Medicaid shortfall, which doesn't have a clear connection to addressing community needs (Wen et al., 2023; Altarum, 2019).

One significant recent example of federal policy impacting the uptake of CE are the Centers for Medicare and Medicaid Services (CMS) regulations released in April 2024 that update how states convene Medicaid member advisory groups through more robust requirements for Member Advisory Committees. The requirements include specifics on committee composition, meeting frequency, public access, reporting, staffing, and "the principles of bi-directional feedback, transparency, and accountability," and require the creation of a member-only advisory group, called the Beneficiary Advisory Council, composed solely of current or former Medicaid members.

4.3 State policy

At a state policy level, there are many examples of how states are supplementing existing federal requirements to provide more specific guidance and reporting requirements on CE in community benefit spending. For instance, five states have set a minimum community benefit spending requirement, and 31 states have a state-level reporting requirement in addition to federal reporting (Wen et al., 2023).

States can also take legislative approaches to require CE in a variety of contexts. One approach is requiring patient and family advisory councils (PFACs) in hospital systems. Currently, Massachusetts is the only state that mandates all hospitals (acute care, rehabilitation, and long-term acute care) to have a PFAC. Under the law, Massachusetts PFACs must meet quarterly, 50% of the PFAC must be comprised of patients or family representatives, and membership should reflect the community served by the hospital (Wachenheim, 2015). Other states are taking smaller legislative approaches to requiring engagement, such as California's requirement for Medi-Cal managed care programs to establish family advisory committees.

Finally, states often delegate some of their community engagement to managed care organizations (MCOs), and many do use their Medicaid waiver authority to establish different mechanisms for CE that meet the needs of specific subpopulations, such as short-term "collaboratives" focusing on topics like non-emergency medical transportation or healthcare for transgender individuals.

Image description: a diverse group of people with lived experience sit around a conference table engaged in conversation

5

The need for more practical, tactical support

A final key finding from our research is that both healthcare professionals and PWLE understand the strategic and operational challenges of implementing and sustaining authentic CE initiatives and want additional support to strengthen their approach and effectiveness. On our survey, "better training/more understanding of how to engage the community" was the second most common response (behind "more funding") when respondents were asked what their organization needs most to improve its use of CE.

The question many healthcare organizations are grappling with is not "is community engagement valuable and should my organization spend resources on it?" but rather "how can I best demonstrate the value, deepen the commitment, and more effectively develop and sustain partnership with people with lived experience?"

At a foundational level, we heard in KIIs and listening sessions that there is a need to advance a shared understanding of what community engagement is, as well as what and how community engagement "best practices" are implemented. Healthcare professionals and PWLE see CE as valuable, but both sides want more support in operationalizing practices that lead to equitable, impactful, and meaningful work together. Interestingly, both healthcare professionals responsible for undertaking CE and PWLE involved in CE initiatives expressed sentiments like "no one has ever trained me to do this work" and "I feel like I'm making it up as I go along."

In listening sessions, many healthcare professionals carrying out community engagement as a part of their formal role – or as an informal responsibility – expressed interest in additional trainings and resources to support their effectiveness in the work as well as an interest in venues where healthcare professionals leading community engagement work could share and learn from one another.

> "The need for community engagement is urgent, but organizations must slow down before they can engage in this work."
>
> *-KII participant*

In KIIs, many PWLE, particularly those with multiple and chronic conditions, are highly active advocates for their own health, but are not aware of opportunities to partner with healthcare organizations at an organizational level to help improve care and experiences. Even for PWLE who are connected with CE work, many feel unaware of or disconnected from community engagement work happening in other communities across the country and expressed an interest to both connect with other people with lived experience doing similar work and to learn from other community engagement initiatives (e.g., other patient family advisory committees) as a way to strengthen their own local work.

Both healthcare professionals and PWLE believe that the approach to and effectiveness of CE is highly dependent on specific community context, but also recognize that there is much that can be learned from others doing this work – if only the space and opportunities existed for people to come together.

SECTION 4

Recommendations to advance community engagement in healthcare

After reviewing major findings from Phase I research, the INSPIRE team developed and categorized a comprehensive list of potential implementation approaches applying a typology developed in the implementation science process known as expert recommendations for implementing change (ERIC). The team then completed a prioritization exercise evaluating approaches based on their impact on the ultimate goal of advancing CE, as well as feasibility of carrying out the strategy. The following recommendations represent the highest priority areas for meaningfully advancing the state of CE in the U.S. healthcare system.

1

Strengthen the practice and impact of community engagement initiatives by increasing access to training and learning communities for healthcare professionals leading the work

Our research findings clearly point to the need for additional practical and actionable support for healthcare professionals leading CE initiatives. Increasingly, CE is becoming a requirement in policy and grantmaking and is seen as a strategic priority by many healthcare organizations. These requirements and commitments are increasing the quantity of CE initiatives across the country, but they are not addressing issues of quality and impact.

There are major gaps in the implementation of CE that prevent the work from reaching its full potential and create a cycle of deactivation where organizations and communities don't experience enough value from the work to warrant further investments and thereby further restrict the potential of future work by relegating CE to be an underfunded, siloed, and secondary activity.

It is not only the responsibility of PWLE to acquire new skills to prepare themselves for partnership work, it is also the responsibility of healthcare professionals leading community engagement work to build the skills and contexts that support authentic engagement, and it is crucial that healthcare professionals have access to the support and resources they need to undertake their work successfully.

There is enormous opportunity to advance CE by focusing on improving the quality of CE where it is already happening, by expanding access to hands-on training and technical assistance for entities with a requirement to undertake community engagement (for instance, D-SNP plans, state Medicaid agencies, etc.). This practical support must meet frontline healthcare staff where they are by providing not only conceptual frameworks, but step-by step guides to real-life applications of CE promising practices, including adapting approaches to meet the specifics of their own community and organizational context. Policymakers and funders must also recognize the challenges healthcare organizations face in appropriately resourcing their CE work and create additional avenues to resource this necessary support.

Despite the recent growth of attention being paid to CE by healthcare organizations, this is not new work. Across the country, there is authentic CE work happening and a huge community of people with substantial experience and expertise in building successful community engagement initiatives and therefore significant utility for CE-focused learning communities and peer-to-peer networks of those doing the work. Every individual and organization member of the INSPIRE team has taken part in building and witnessing meaningful CE in action. There is enormous opportunity to support skills and knowledge exchange across the national community of people dedicated to authentic CE simply by creating the opportunities and structures to do so.

2

Prioritize leadership development and capacity-building for PWLE – particularly those from under-represented communities – to step into partnership roles

Meaningful partnerships are built when all parties have access to the resources, knowledge, and supports they need to authentically engage with one another. While there is much work for healthcare organizations to do to foster authentic, inclusive, and accessible contexts for CE, PWLE are also interested in building their skills to be successful in partnership roles.

Many people navigating healthcare as patients and family caregivers are highly adept advocates for their own personal healthcare but have limited experience with or access to opportunities to advocate and advise at an organizational, systems, or policy level. There are discrete skills and competencies that help people move from individual-level advocacy to engagement and partnership roles, which include how to identify and access these opportunities.

Even for PWLE who have substantial experience at organizational, systems, and policy level work, many express a desire to build their skills and to connect with other people doing similar work across the country. PWLE who contributed to our research consistently requested better access to training, mentorship, and peer learning opportunities to equip them with the skills and knowledge to effectively engage with healthcare organizations as equal partners. While there are existing national models geared towards meeting these needs (such as the National Consumer Scholars program and PFAnetwork) and resources available for local organizations to train and support PWLE (such as these tools from National Healthcare for the Homeless Council and Resources for Integrated Care) many opportunities remain to bolster awareness and access to meet the needs of PWLE across the country.

Top of mind for healthcare leaders and PWLE is the diversity gaps in current CE initiatives. Very often, people from communities most proximate to the harms and inequities of our current healthcare systems and policies (e.g., people from communities impacted by structural racism, people with disabilities, people impacted by poverty, etc.) are the least likely to be at the table of healthcare organizations' CE work. To close these gaps, it is essential that we partner with people from the communities that are often under-represented in CE, and that we build out tools and resources that expand awareness of and access to pathways for building community power through CE.

Image description: a group of four people with lived experience pose for a picture while attending a healthcare conference

3

Improve organizational-level infrastructure to support high-quality and impactful community engagement

In addition to directly supporting those doing CE work through peer-to-peer connections and skills and knowledge building, to meaningfully advance CE in healthcare we must also further develop the organizational-level systems, policies, and frameworks that support CE initiatives and healthcare professionals to be successful. Successful community engagement requires that healthcare organizations do internal work before reaching out to the community, including investing in CE infrastructure internal to the organization.

One approach to support this process is to develop community engagement Practice Profiles, a tool used by implementation scientists to support the adoption of evidence-based practices in healthcare. While development of an evidence base for CE is still in nascent stages, there is significant experiential wisdom and evidence that could support creation of actionable guides that not only describe exemplar case studies of CE, but define the who, what, where, and when of replicating and adapting meaningful CE initiatives.

Another crucial aspect of CE infrastructure is impact measurement. The Assessing Meaningful Community Engagement in Health and Health Care Policies and Programs working group convened by the National Academy of Medicine has developed a toolkit to support CE impact measurement including a conceptual model, series of case studies, and comprehensive library of measurement instruments that has significantly advanced the ability of those engaged in CE to undertake evaluation and impact measurement.

An important next step is to enable application of these tools in "real world" CE initiatives that are often strapped for resources for implementation, let alone for evaluation, and to move towards some alignment on impact measurement approaches. Currently, the NAM library of CE assessment tools includes 28 instruments. While different approaches to measurement have advantages in meeting the diverse needs and approaches of diverse communities and CE initiatives, it is also inhibiting the field from moving towards a widely accepted set of "best practices" that hold up across contexts and settings.

Finally, as discussed earlier in this report, while it is vital to recognize that the value of CE to PWLE and to organizations goes far beyond financial considerations, it is undeniable that for healthcare leaders, cost-effective investments will always remain a top concern. We consistently heard that "lack of resources" is one of the primary limitations for advancing CE. Very few healthcare organizations include CE activities in organizational and departmental budgets, which could help increase sustainability as compared to relying on time-limited grants and philanthropic dollars. However, to do this, healthcare leaders must clearly understand how investments in CE make financial sense. Therefore, not only should future development of CE measurement approaches move the field towards a clearer set of culturally relevant and evidence-based "best practices," but they must also work to connect impact measurements to financial outcomes to support development of a business case for CE that justifies broader organizational adoption and investment.

4

Address structural and policy opportunities that impact the uptake of community engagement

While our first three recommendations represent shorter-term options to meaningfully advance CE in healthcare, there are also several approaches to address structural- and policy-level opportunities that could substantially change the landscape for adoption of CE across healthcare, but are likely to be longer-term endeavors. However, to ensure any structural or policy change approaches achieve their desired aims, it is essential that they are crafted and implemented in partnership with PWLE, and that they prioritize incentives rather than penalties to address the dire need to properly resource CE work.

As discussed earlier in this report, there are many ways for state and federal policies to require CE activities, such as CMS' regulations for how states convene Medicaid member advisory groups and Massachusetts' requirement for hospitals to maintain patient/family advisory committees and California's requirement for Medicaid (Medi-Cal) managed care plans to have family advisory committees.

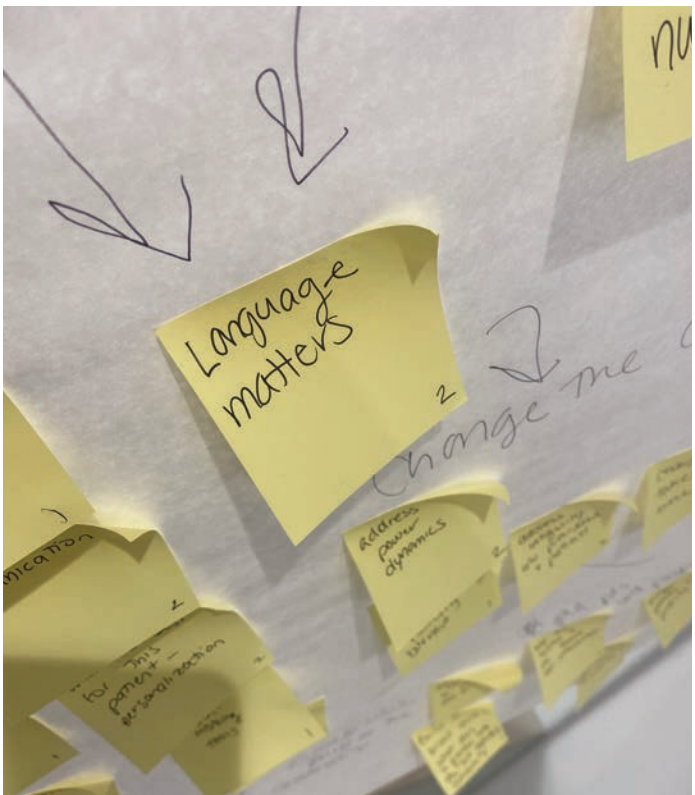

Image description: a yellow sticky-note on a white poster board reads 'Language matters'. Two arrows have been drawn on the poster board pointing to this note

Currently, there are few legislative requirements for healthcare organizations to undertake CE, and even those in existence are often vague and limited in their scope. While policy change on its own is unlikely to address quality and fidelity considerations for authentic implementation of CE, expanded requirements can ensure that CE activities are happening at all. Alongside increasing policy requirements for CE, it is equally important to advance opportunities to strengthen existing policies through clarification in the legislation of who "community" refers to as well as enhancing spending and reporting requirements — such as ensuring a greater portion of community benefit dollars are allocated towards activities that PWLE have had a meaningful stake in identifying.

Accreditation in healthcare is an external review process that shows that a healthcare organization is meeting regulations and standards defined by an external accreditation organization. Ideally, accreditation helps to improve quality and efficiency and acts as a signal to others that an organization has achieved a specific level of status and proficiency in a given area. Creating a CE accreditation or including CE as a component of an existing accreditation — such as health equity accreditation — would be an important step in building structural support for CE across healthcare. Not only would this provide incentives for healthcare organizations to invest in their CE competencies and practice, but it would also provide transparency for community members and organizations to understand which organizations were "walking the talk." However, in order to create a CE accreditation process, it is necessary to first build out a consistent impact measurement approach for CE.

Role-specific recommendations for advancing authentic community engagement

Role of healthcare executive leaders

Organizational initiatives survive and thrive with leadership commitment and dedication, and the role and responsibility of healthcare leaders in advancing community engagement cannot be overstated. To advance community engagement, healthcare leaders can:

- Employ community engagement as an **ongoing organizational strategy** integrated across departments and service lines to ensure that policies, programs, and processes meet the needs of patients and communities.
- Strengthen the impact of **investments in social determinants of health** initiatives by utilizing authentic community engagement to inform these efforts.
- Create **workforce roles** such as peer specialists and community health workers that center lived experience.
- Fulfill verbal commitments to community engagement and patient-centered care with **actions that demonstrate that commitment**.
- Support integration of community engagement across departments and service lines as a **quality improvement practice** that is informed and led by people with lived experience.
- Ensure community engagement is positioned for impact by **investing adequate resources** such as staff time, training, and compensation for people with lived experience who participate.

Role of healthcare professionals leading community engagement work

Because of their daily involvement in CE activities and their interactions with PWLE, healthcare professionals leading community engagement work are uniquely positioned to identify and champion effective CE strategies. To advance community engagement, healthcare professionals leading community engagement work can:

- Adopt practices that support authentic community engagement by **utilizing INSPIRE's Nine Dimensions framework** and the resources referenced in this guide.
- Document the impact of community engagement by **measuring success and sharing outcomes** back with healthcare leaders and the community alike.
- Consistently **credit people with lived experience** for their contributions and role in shared work.
- Drive organizational accountability to mission statements and messaging about community engagement by **advocating for the resources and support needed** to meet words with action.
- Identify existing community groups and other staff/departments/organizations already engaged in authentic relationships with people with lived experience and **respectfully leverage these existing channels** before creating something new.

Role of funders (philanthropists and grant-makers)

By focusing on providing channels for both support and accountability, funders, philanthropists, and grant-makers have a huge role to play in ensuring authentic CE becomes the norm rather than the exception in healthcare. To advance community engagement, funders can:

- **Undertake authentic community engagement within your own work** to ensure grant opportunities, contracts, financial incentives and project outcome measures are reflective of community priorities, needs, and preferences.
- Make sustainable investments that provide **ongoing and flexible resources** to reflect the reality that authentic relationships with community are built over time and with sustained effort.
- Address the gaps and uncertainties for implementing and sustaining authentic community engagement addressed in this report by **creating channels for grantees to access resources** to support them in their work.
- Create recommendations, supports, and guardrails to ensure funded initiatives **provide fair and equitable compensation to people with lived experience** who participate.
- Incorporate the value of community engagement into reimbursement structures, performance measurement systems, and other systems of **healthcare accountability**.

Role of PWLE

As noted earlier in this report, CE benefits from the rich history of PWLE creating transformative change by speaking up on the issues impacting them. While it should never be the sole responsibility of people most proximate to the harms done by our current systems and power structure to bring about change on their own, PWLE can choose to play a vital role in holding healthcare organizations accountable for carrying out authentic CE. To advance community engagement, people with lived experience can:

- Call attention to gaps in diversity within existing community engagement initiatives and partner with organizations to **engage the people and communities missing from the conversation**.
- Share perspectives and experiences of barriers to partnership along with ideas to help organizations develop CE approaches that **address barriers to engagement**.
- Use the frameworks and language in this report to **request clarity on organizations' community engagement work, goals, and strategies** — including requesting mechanisms for closing the loop on outcomes of shared work and transparent policies for compensating people with lived experience.
- Help organizations **identify existing community groups and community-led initiatives** that they can support and connect with, before beginning something new.
- **Call attention to the role and contributions of people with lived experience** in advancing goals shared by community and healthcare organizations to highlight the impact and importance of community engagement.

Role of policymakers

Policymakers committed to equity can make enormous strides by thoughtfully advancing policies that provide the opportunities and resources for authentic community engagement to thrive. To advance community engagement, policymakers can:

- Engage people with lived experience and healthcare professionals in the **creation of community engagement requirements** to ensure they achieve the best outcomes.
- **Address the lack of financial resources** — a primary barrier to community engagement work — through incentive and reimbursement pathways.
- Incorporate CE as a **funded component of Medicaid 1115 demonstration waivers**.
- Strengthen the impact of community benefit legislation by:
  - Expanding community health needs assessment (CHNA) requirements to meaningfully include people with lived experience throughout the process
  - Requiring that healthcare organizations allocate an appropriate, defined percentage of community benefit spending to activities related to authentic community engagement

Role of community-based organizations

While community-based organizations (CBOs) are not a primary audience for this report, we must acknowledge the significant work so many CBOs have done to build authentic and trusting relationships with their communities. Many healthcare organizations turn to CBOs as their first stop for how to connect and engage with people with lived experience, and CBOs – for better or worse – are often implicated in the way healthcare organizations approach community engagement. To advance community engagement, CBOs can:

- **Share and promote your best practices** for engaging authentically with people with lived experience to support healthcare organizations in adopting similar approaches.
- Safeguard the trust and relationships you have built with community, by **requiring transparency, authenticity, and accountability from healthcare organizations** that seek to engage with you as an entry-point into your community.
- Amplify the voices of people with lived experience — rather than just speaking on their behalf — by **creating space for people with lived experience to be directly involved** in projects and initiatives.
- Support the growth and capacity of people with lived experience by **connecting them to opportunities to work with healthcare organizations** as advocates and advisors.

Image description: A mixed group of healthcare professionals and people with lived experience sit together in small group discussions

SECTION 5

Conclusion

Over the past year, the INSPIRE Core Team has been honored to hear from so many people across the country who are committed to and engaged in authentic CE.

Overwhelmingly, our team feels that the findings from our research are not surprising but are extremely validating of the experiences we all have day-to-day in building authentic partnerships between PWLE and healthcare organizations and supporting others to do the same in their communities. We are heartened by the many dimensions of value people experience from doing CE, we are motivated by this moment in time where there are tangible opportunities to advance and strengthen the work, and we are INSPIREd by the community we have built on our Core Team and through our extended networks of hundreds and hundreds of people who have contributed to and expressed such interest in this project.

Above all, we end by reflecting that so much of the value derived from people doing CE is deeply personal. The value is felt through the relationships that are built, the connections that are made, and the opportunity for people to transform their personal suffering and struggles into an easier road for others like them and a brighter future for their community. At its core, CE is deeply human and humanizing work. The end goal of CE should always center well-being, and the process of CE itself should facilitate this for all involved.

We are at an important moment of opportunity for CE. High interest across healthcare in undertaking CE is beginning to be translated into action. The findings and recommendations in this report provide a roadmap for how healthcare organizations and people with lived experience across the U.S. can realize the full potential of authentic CE to build trust, advance health equity, create cost-savings and efficiencies for healthcare organizations, and foster healthy and thriving communities.

Read these supplemental materials at: camdenhealth.org/INSPIRE-report

- Field survey – Final summary
- Key informant interviews – Final summary
- Listening sessions – Final summary
- Literature analysis
- Business case brief

Other publications and media:

- The nine dimensions of authentic community engagement (brief)
- You can't advance health equity without effective community engagement (blog)
- Are we speaking the same language? Defining what we mean by "community engagement" (blog)
- Caring as Communities #27 - INSPIRE Project (podcast)
- Community Engagement stories - Soapboxx (video)

Image description: members of the INSPIRE team sit around a conference table smiling exuberantly during a meeting

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INSPIRE partners

Organizations

Camden Coalition

Community Catalyst

the center to advance consumer partnership

PFCCpartners
Patient & Family Centered Care

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®
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People with lived experience


Burt Pusch


Rebecca Esparza


Carlos Benavides


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LaRae Cantley


Stephanie Burdick

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