

EXECUTIVE SUMMARY

# A roadmap for effective community engagement in healthcare

Final report from  
INSPIRE Phase I

July 2024

**inspire**

*community engagement  
for better healthcare*



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

# 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 initiatives
- 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.



## INSPIRE partners

### Organizations



### People with lived experience



Burt Pusch



Rebecca Esparza



Carlos Benavides



Savina Makalena



LaRae Cantley



Stephanie Burdick