All In: Data for Community Health Affinity Group

Learning Goals

Affinity Group Name: Developing Meaningful Measures by Centering Community Voices

Organization Name: American Institute for Research (AIR)

Point of Contact(s):
Facilitator(s): Karen Frazier (kfrazier@air.org) and Stephen Hoy (stephen@pfccpartners.com)
All In support staff: Natrina Kennedy (natrina.kennedy@iphionline.org)

Group Leader (Subject Matter Expert) Areas of Expertise: Partnering with community members including clients, families, and others with diverse lived experience* to co-create measurement that drives equitable health outcomes. (*See definitions below)

Affinity Group Composition:
We welcome:

- All In Online Community who are practitioners involved in supporting or leading collaborations that actively include community members or people with lived experience and are interested in using measurement and data to improve community health.
- Practitioners who are not yet partnering with community members or people with lived experience but would like to gain experience forming collaborative partnerships with community members around measurement and multi-sector data sharing efforts.
- Individuals and/or teams who are ready to learn, engage in rich discussions, form collaborative partnerships, bring a solution-focused mindset, and embrace the value of lived experience and diverse voices in the work of measurement and multi-sector data sharing.
- Members of the All In Online Community are encouraged to join this group if the topics of discussion will help you advance your work.

For those that are not members of the All In Online Community and still want to participate, please email Natrina Kennedy (natrina.kennedy@ilphionline.org) program staff, to be added to the group, be included in updates, meeting invitations and to access resources and notes.

There is no limit to the size of the group. The group meetings will rely on sequential learning so it would be best to have all interested individuals or teams participate in the group from the beginning. The first meeting will be particularly important as we will spend time level-setting as a group.

Description of group:

Although multi-sector data system integration can seem like a task reserved for data analysts or statisticians, the foundational work starts with conversations around understanding what people want to measure through data to show impact and improve outcomes. This affinity group is designed to support conversations around how to partner with community members and people with lived experience to develop, select, and use measurement in ways that reflect the strengths, priorities and vision of those directly impacted by the result of the data integration.

Learning Goals:

1. Learn how to build and sustain trusting relationships with people with lived experience to elevate community power in data sharing efforts.

2. Practitioners and partners learn how to co-create measurement such that clients, families, and others with diverse lived experience drive what is measured, when and by whom data is collected, what data is used and how, how harm and unintended consequences from measurement are monitored and assessed, and who ultimately acts on measurement and in what ways.

3. Learn how to focus measurement on what communities know matters most to their health and well-being, how to be intentional about equitable partnerships, and how shared measures can align systems around people to advance equity.

By the end, participants will leave with the knowledge, skills, and experience to work in partnership as they define and prioritize measures for multi-sector data sharing. These partnerships will include people with lived experience—especially those who historically have been underrepresented in data sharing efforts—and community health practitioners from varied disciplines.

Meeting schedule: This section to be completed upon initial contact with members.

Resources:

1. [Guiding Principles for Aligning Systems with Communities to Advance Equity through Shared Measurement](#)
2. [The Case for Patient-Centered Measurement](#)
3. [Lessons Learned from Patient-Centered Measurement Pilots](#)
4. [Patient Family Advisor Summit on Measurement Outcomes summary](#)
5. All In will provide the link to the All In Online Community group where notes and meeting schedule will live
6. All In: Data for Community Health website
   a. https://www.allindata.org/

7. If you're new to the All In learning collaborative, the first step to join is to sign up for the online community (community.allindata.org) and create an individual member profile. Read our FAQs for help getting started.
8. All In 101 webinar introduction to All In: Data for Community Health, online learning collaborative
    a. https://vimeo.com/487432652

Definitions

Person with lived experience or community member: A person with lived experience is someone who has lived (or is currently living) with the issues a community is focusing on and who may have insight to offer about the system as it is experienced by consumers (e.g., a woman who was formerly or is currently experiencing homelessness who can offer insight into that experience). They will have:

- Expertise that doesn't come from training or formal education.
- Knowledge from an experience with an issue or challenge.
- Direct experience with a system, process or issue, or trying to engage with a resource.
- Awareness of what works, what doesn't work, and what resources (formal or informal) are available in the community.[b]

Community: Community has no single definition. It can refer to geography or a group that self-identifies by age, ethnicity, gender, sexual orientation, disability, illness, or health condition. It can refer to a common cause, a sense of identification or shared emotional connection, shared values or norms, mutual influence, common interest, or commitment to meeting a shared need.[a]

Measurement: Measurement is a way of using data to set goals, monitor progress, or evaluate success. Organizations and systems use measurement to guide decisions, allocate resources, identify areas for improvement, evaluate what works and what doesn't, and promote accountability. The process of measurement includes defining what to measure and why that's important; choosing specific metrics, data sources, and methods; using data to calculate a metric and making sense of what that metric means; and sharing that information in ways that are easy to understand.

[a] Community-Campus Partnerships for Health. Frequently asked questions.
https://www.ccphealth.org/frequently-asked-questions/

[b] Getting Started - Engaging People with Lived Experience. Engaging people from Lived Experience Toolkit.
https://www.communitycommons.org/collections/Engaging-Lived-Experience-Toolkit