Gathering Input from Individuals Experiencing Inequities: Practical Facilitation Guidance

AHE Advancing Health Equity
Leading care, payment, and systems transformation

Updated March 2023

Getting first-hand input from individuals experiencing inequities is essential to successfully reduce or eliminate inequities in health and healthcare. It is best practice to ensure that your care transformation and payment mechanisms are community-centered and developed in partnership with individuals most affected by the targeted health inequities. These partnerships will help ensure that your care transformation and payment mechanisms are relevant and meaningful for those they are designed to serve.

Insights from individuals experiencing health and other inequities will benefit the work in many ways, including the discovery of key points and ideas that may be applied to other quality improvement efforts. The benefit is not just in the resulting knowledge, but in the process of building relationships with individuals experiencing inequities, the community at large, and local partners such as staff at community-based organizations (CBOs). These relationships are necessary to deliver high quality and high value healthcare that decreases health disparities.

In an ideal world, individuals experiencing inequities are true partners in the work to address such inequities. These individuals would be at the table at the beginning of the work and would continue to be equal partners throughout the entire duration of your care delivery transformation and payment reform efforts (e.g., are a part of the core Learning Collaborative team or an accompanying governing structure that actively participates in discussions and decisions related to care delivery transformation and payment reform). In this scenario, ideas, suggestions, and feedback would be incorporated into care delivery transformation efforts and individuals experiencing inequities would have equal decision-making power.

It may take years and a great deal of effort to get to this ideal state. The following key considerations for working with and obtaining feedback from individuals experiencing inequities and CBO staff members may at times be more relevant to earlier, information-gathering efforts or to more advanced partnership

Tools for Hosting Focus Groups

The focus group resources in the reference list on the www.forces4quality.org lessons learned website and Exhibit C *(page 10)* in Reducing Health and Health Care Disparities: Implementation Lessons and Best Practices for Health Care Organizations contain valuable and detailed information on running focus groups and may be particularly useful to LC teams in the earlier stages of community and member engagement.

efforts. Regardless, community and member engagement in any form should be a priority, even as organizations are also undergoing a larger effort to build power-sharing relationships with individuals experiencing inequities.

The equity-specific considerations that follow will be useful when designing group or one-on-one engagement efforts during the root cause analysis, care delivery transformation design, payment model design, and evaluation efforts of your AHE initiative. Please note, this document is not designed to be a fully comprehensive resource. The Advancing Health Equity team can provide more resources to support efforts around partnering with individuals experiencing inequities.

On Methodology

People from different cultures approach group dynamics differently and define what is private in different ways. Focus groups or public meetings and group discussions may not always be the ideal method for gathering information. You might find that you get more responses and richer results using other methods, such as one-on-one conversations or anonymous surveys. Pilot test the data collection process and materials with a small number of individuals and plan enough time to make revisions before full-scale efforts begin.

Selecting a Moderator, Facilitator, or Interviewers

It is recommended to select moderators/facilitators (for group engagements) or interviewers (for one-on-one engagements) who share core identities with participants (e.g., racial or ethnic identity, sexual orientation, gender, immigrant status). Moderators with shared characteristics can increase chances for implicit trust, a shared understanding of relevant issues, and common experiences among marginalized populations. A shared identity can facilitate communication between the moderator/interviewer and participants.

Moderating focus groups or other styles of group engagements is a high-level skill that requires training, complex decision making, and judgment calls about strategy. These skills vary based upon individual and interpersonal dynamics within any particular group. Unskilled or inexperienced moderators may unintentionally impact the quality of information gathered (e.g., missing pertinent information or over-emphasizing less important information) and the quality of the interaction overall (e.g., uncertainty about how to react to difficult topics, not noticing relevant changes in group sentiment). Thus, in situations where an interviewer/moderator who is both identity-concordant and skilled is not available, it is advisable to prioritize the skill and experience of candidates.

In addition, the perception of and response to the moderator/interviewer can be affected by your organization’s relationship with the community, local and national politics (e.g., immigration policies and debates), and prior personal experiences of group members with the organization. Selecting a moderator/interviewer requires intimate knowledge of these contextual issues, as well as the needs and preferences of individuals experiencing inequities. Community advisory boards and CBO partners who work with individuals experiencing the specific health inequities may have deeper knowledge of this context and can provide guidance and recommendations for organizations seeking to engage or partner with communities and members.

Recognizing Intersectionality in Marginalized Groups

Individuals hold multiple core identities (e.g., race/ethnicity, gender, clinical diagnosis or health status, age, sexual orientation, disability status) and any one of these identities may affect the way in which a community member experiences a targeted health inequity. It may be appropriate to hold multiple focus groups, meetings, or other types of opportunities for engagement that consider different aspects of intersecting identities. For example, in some cultures gender may bear a significant influence on how individuals respond to being diagnosed with a particular health condition and their subsequent lived experience. In this case it may be advisable to hold separate sessions, with different moderators, for men and women – and also critically important to identify if any participants identify as transgender, non-binary, or gender non-conforming and require additional accommodation. In this case, if a qualified moderator/interviewer who shares the community members' multiple relevant identities cannot be found, it might be appropriate to prioritize gender matching over other identity concordance.

Community Networks and Social Desirabilty

Some populations experiencing inequities have small formal and informal networks with few degrees of separation between individuals. In communities with small networks, selecting a moderator/interviewer who is well-known and highly regarded can increase participation in focus groups or other engagements and can foster feelings of trust. However, group discussions may cover information that is socially undesirable in the community (e.g., low medication adherence due to substance use, struggling with depression in cultures where mental health challenges are stigmatized). In such cases, it may be preferable to select a moderator who is not prominent in the community, so participants are less reluctant to disclose sensitive information. Alternatively, it may be more useful to pursue alternative engagement opportunities (e.g., one-on-one conversations) that allow community members to maintain privacy when discussing sensitive topics.

Report Back

Always report results back to those who provided input and partnership on designing and implementing initiatives. Suggestions that were incorporated into the design of the equity activity should be noted and contributions of community members should be acknowledged. Suggestions that were not incorporated into the design of the equity activity should be recognized and the reasons for not including them discussed. Finally, be prepared with concrete next steps to maintain the spirit of inclusion, momentum, and a culture of equity.

Advancing Health Equity: Leading Care, Payment, and Systems Transformation (AHE) is a national program supported by the Robert Wood Johnson Foundation and based at the University of Chicago. AHE's mission is to discover best practices for advancing health equity by fostering payment reform and sustainable care models to eliminate health and healthcare inequities.

www.advancinghealthequity.org

Robert Wood Johnson Foundation