

Getting Feedback from Patients

Getting first-hand input from your priority population is essential to successfully address racial and ethnic disparities in care. If properly gathered and integrated, patient feedback will ensure that your equity activity is relevant and meaningful for those it is designed to serve.

Information from your priority population will benefit the organization in multiple 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 patients and community members. These relationships are necessary for organizations with a mission of delivering high quality and high value healthcare.

There are many topics that could be covered in this document and it should not be construed as a comprehensive resource. However, we have selected some key considerations for getting feedback from patients to inform your root cause analysis, equity activity design, pilot testing and evaluation efforts:

Methodology

Patients from different cultures approach group dynamics differently and define what is private in different ways. Focus groups may not always be the ideal method for collecting input. You might find that you get more responses and richer results using other methods, such as 1-on-1 interviews or anonymous surveys. Pilot-test the data collection process and materials with a small number of individuals from the priority population and plan enough time to make revisions before full-scale efforts begin.

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Focus Groups

We strongly encourage you to review the focus group resources in the reference list on the Moodle website at www.forces4quality.org. They contain valuable and detailed information. The following topics focus on equity-specific considerations when designing and running focus groups.

Selecting a moderator

It is recommended to select moderators who share a racial or ethnic identity with participants. These moderators increase chances for implicit trust, a shared understanding of relevant issues, and common experiences among minority patients. A shared racial or ethnic identity can facilitate communication between the moderator and participants, resulting in high quality information.

Moderating focus groups is also 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). Thus, in situations where a racial/ethnic concordant and skilled moderator is not available, it's advisable to prioritize the skill and experience of candidates.

In addition, the perception of and response to the moderator can be affected by the organization's relationship with the community, local and national politics (e.g., immigration policies and debates), inter-agency politics and prior personal experiences with the organization. Selecting a moderator requires intimate knowledge

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of these contextual issues, as well as the needs and preferences of the priority population. We highly encourage you to lean on the expertise of your CAB and CBO partners who serve the priority population to provide guidance and recommendations.

Priority populations with multiple, disparity-relevant identities

Individuals hold multiple core identities (e.g., gender, clinical diagnosis or health status, age, sexual orientation, disability status) and any one of these identities may be relevant to the targeted disparity. It may be appropriate to hold multiple focus groups targeting different aspects of the priority population's relevant identities. For example, in some cultures gender may bear a significant influence on how patients respond to being diagnosed with, and live with, a particular health condition. In this case it may be advisable to hold separate groups, with different moderators, for men and women. If a qualified moderator who holds both identities cannot be found, it might be appropriate to prioritize gender matching over racial/ethnic concordance.

The intersection of community networks and social desirability

Some priority populations have small formal and informal networks with few degrees of separation between individuals. In communities with small networks, selecting a moderator who is well-known and highly regarded can increase participation in focus groups and foster feelings of trust. However, be aware that focus 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 that participants are less reluctant to disclose sensitive information.

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No matter how you get input, be sure to report back to those who participated.

Good suggestions that were not incorporated into the design of the equity activity should be recognized and the reasons for not including them discussed. And finally, be prepared with tangible next steps to maintain the spirit of inclusion, momentum, and a culture of equity.