

Accurate, detailed data will help your team determine which health inequities need to be addressed. This document describes major considerations to take into account before you begin exploring your data and recommendations to guide your work in identifying a health equity focus.

1. Define key terms

Definitions matter. Create standard definitions of major terms and categories that are central to your initiative whenever possible. Those common definitions should be readily accessible to all partners and stakeholders. It may help to create a glossary of terms as well as a rationale for why certain definitions are used instead of others. Defining key terms provides necessary clarity when it comes to using data and will put your team on the path to success.

It's important to use precise definitions, especially when drawing conclusions from data that uses words within similar categories or with similar meanings. For example, in a multi-organization collaborative one organization partner might define smoking status as a person who uses nicotine products exclusively. Another may define "smoker" as someone who uses nicotine and/or marijuana products. If you are collecting demographic information related to gender identity, language, or ethnicity/race, data reporting can become muddled if partners are using different definitional criteria.

2. Include Patients

Patients are more than recipients of care. They are people who are integral to the overall success of your initiative. They should be part of the decision-making team when planning how data will be used for the initiative, including any new data collection procedures, such as screening for social needs or obtaining sensitive demographic information.

Patients will have unique insight, questions, and concerns about how data should be collected and used and the types of care transformation they would like to see. Keeping their needs and concerns at the forefront by working in partnership with them from the beginning will go a long way to creating a care transformation that is meaningful for everyone.

3. Outline the benchmarks of success

While having multiple stakeholders strengthens your team, it also means that they will



likely have different ideas about what inequities are most important to address. It is important to gauge what each stakeholder values. Are they most concerned about patient or member satisfaction? Perhaps they are invested in meeting contractual obligations of partner organizations. Maybe they want the initiative to both eliminate inequities and also improve the work environment for employees. Some may wish to intervene in social drivers of health such as access to affordable and healthy food, or safe and affordable housing in order to influence multiple health outcome measures.

Understanding each stakeholder's values will make it easier to identify overlapping motivations and goals of all stakeholders. These areas of overlap are where common ground and shared motivations will emerge that will help you identify your health equity focus.

4. Obtain Buy-in

Organization and team member buy-in is necessary to collect, maintain, and utilize accurate data. Most teams utilize existing data to identify their health equity focus, but some may decide to collect new data. Regardless, many stakeholders will be involved in accessing, potentially sharing, analyzing, and interpreting data. Team members should understand why the data is being collected or accessed and to what purpose. Take time to explain the initiative's importance and its role in improving care and health outcomes for patients. Obtaining buy-in, however, also requires providing team members adequate training, administrative support, and resources. If team members will be asked to collect new data, they should also receive additional training on methods for obtaining sensitive information from patients.

5. Increase consistency of data processes

Regardless of staff training, there may still be inconsistencies in how data is collected from patients and reported in the electronic health record (EHR). This is especially true in a multi-organization collaborative or when all health care providers in a single system use different EHRs or healthcare quality metrics. Even within a single system, how specific units and teams collect and enter data in EHRs can inadvertently diverge over time. As a team, you should decide how and where any new data will be collected and stored. If data will be collected at different locations or in different systems, for example, consider using a central storage location, such as a shared database.

You should also decide which person or group will be responsible for ensuring data collection and reporting processes are followed and plan for periodic refresher sessions



that reinforce data collection, analysis, and reporting procedures.

6. Determine which data to continually update

During the planning process, keep in mind the needs of stakeholders who are instrumental in determining the sustainability of your initiative. Several of them may require different process or outcome data than what your team is utilizing. Taking time to verify in advance the data that key stakeholders will want in the short-, mid-, and long-term, including the report format and cadence, will save your team time and energy in the long run. Each stakeholder may need different process or outcome data.

7. Secure permission to share data

Teams may need to request permission to gain initial access to data to identify disparities and maintain access over the lifetime of an equity initiative. There are several key questions teams should ask when thinking about permissions to use data:

- Are one or more Data Use Agreements (DUAs) needed?
- What are the processes and timelines for generating the necessary DUAs? DUAs
 often require several levels of review and approval at each organization
 involved.
- Are all individuals and organizations involved in sharing data HIPAA compliant?

Remember that some regulations may preclude sharing sensitive data, such as data related to substance abuse disorder and mental health diagnoses. Proactively identify the relevant regulations and protocols if your initiative wishes to utilize sensitive patient-level data.

8. Plan the Details in Advance

Complex multi-faceted initiatives and those with multiple organization partners will likely need data from multiple sources. For example, an initiative with health care providers, a Medicaid-managed care organization, one or more state agencies, and community-based organizations may need many or all of the partner organizations to contribute the necessary primary and secondary data.

Determine which stakeholders will be responsible for collecting, pulling, merging, reconciling, and analyzing data from various sources, including patient-level, claims, and other types of data. Here are some key questions:

Identify A Health Equity Focus: Key Data Considerations and Recommendations

- Has the team agreed upon a common definition and format for data points in advance of collecting any new data?
- Will the team need to merge data sets from multiple organizations?
- Will there be a need to translate or transform certain data points from different sources in order to merge them into a single data set? For example, do partners use different thresholds for the same quality measure?
- Has the team confirmed that they have a correct understanding of where data is currently stored, its current format, its level of quality and completeness, and the processes for accessing and extracting it? It is common for teams to discover late in an initiative that their assumptions about the quality of data, its level of completeness, and ease of accessing it were overly optimistic.
- Will the personnel needed to accomplish data-related activities (e.g., IT specialists, data analysists) be available at the right organizations and at the right times (e.g., IT specialists, data analysists)? We recommend confirming in advance with relevant supervisors and teams that the necessary time and resources will be available.

9. Conduct Trial Runs

It is important to design and utilize trial runs of all data collection, pull, transfer, merge, and analysis procedures **before** they are needed for implementing care or payment transformation initiatives. While trial runs themselves take time, they will reveal unanticipated challenges that can be resolved early. Doing so will reduce future stress and timeline delays caused by unexpected challenges once the equity initiative is underway.