

Considerations in Collecting Data to Identify & Reduce Disparities

Using data to reduce disparities requires accurate and timely data. Without it we have an inadequate understanding of who our patient populations are, their experiences, and the communities in which they live. Assuming these may inadvertently perpetuate biases and keep populations that have been disadvantaged and underserved – and the disparities and inequities they face – hidden.

And while race, ethnicity, and language (or REaL) are the most commonly collected demographic data when looking at disparities, there are many categories to consider. For example:

- Race
- Ethnicity
- Language
- Age
- Sexual Orientation
- Gender Identity
- Education
- Religion
- Physical/Intellectual Ability
- Tribal/Indigenous Affiliation
- Income
- Incarceration Status
- Citizenship Status
- Employment

However, collecting such data is often a challenge for many practices. Below are some considerations as you begin to develop and/or implement your own data collection plan.

1) Provide all staff with adequate training and education to ensure consistent, meaningful, and respectful collection of patient data.

- Educate staff on why they're being asked to collect this data, the role they play, and how it will impact their work. Leaders should regularly communicate this 'why' to staff. Also, ensure staff are ready to answer patient questions as to why they are asking for this information. Some practices have also provided brochures to educate patients on why they are requesting certain data.
- Train staff on how to collect and store the data. One strategy is to provide staff with common scripts to consistently interact with patients in collecting data.
- Asking questions about demographics and social identity to patients can do more harm than good when approached in the wrong (i.e., insensitive) way. Ensure staff are trained in cultural responsiveness as well as how to communicate respectfully with patients about data collection.

2) Make sure data is patient-reported – staff should never assume or guess a patient's response.

3) Data used to identify and reduce disparities can come in many forms and from many places.

However, data should be:

- Accurate (are data self-report and correctly reported?)
- Unique (is each patient only counted once?)
- Timely (are data updated regularly?)
- Consistent (are data internally consistent?)

Consider national, regional, and state resources that are available – this way, you do not need to start from scratch or wait to access and analyze internal patient-reported data.

- Examples include County Health Rankings, local community health needs assessments, and government agencies, such as state public health departments.

Partner with community-based organizations that can provide insights into social or cultural differences and inequities in the community served and inform strategies to reduce disparities.

- 4) There will likely be unanticipated EHR-related challenges.** Do not allow challenges in generating EHR reports on care process and outcome measures, stratified by patient demographics, to stall your progress. Examples of alternative means of accessing some of your desired information while you work to resolve any challenges include:
- Manual extraction of a smaller sample set of data.
 - Manipulation of data outside of your EHR system.
 - Working with IT staff to develop software workarounds.
 - Collecting qualitative data on perceived disparities as an alternative to quantitative data.
 - Using population-level data to inform decisions about disparities to target.
- 5) If data isn't collected, characterize the missing data, including those labeled "unknown" or "refused".**
- Segment missing data to determine opportunities to improve your data collection process. If you have high rates of missing data (including for specific conditions or diagnoses), do not simply ignore those patients in your analysis – this will likely bias any results you may find.
- Common reasons for failure to adequately collect and record data include:*
- Inconsistency across practice staff regarding where certain quality data should be entered.
 - Lack of clarity on the order and/or definitions of the race and ethnicity categories.
 - Hesitation among staff about how to coach patients on the data collection process.
- 6) Collect qualitative data from patients, staff, and community stakeholders to inform your interpretation of stratified measures as well as the design of interventions.** Surveys, questionnaires, and focus groups can be invaluable in eliciting the root causes of a disparity.
- 7) Remember, trust in healthcare organizations and staff impacts patients' willingness to share information such as race, ethnicity, sexual orientation, and so on.** A key to collecting meaningful patient information needed to identify and reduce disparities is addressing shortcomings when it comes to your current and historical patient and community relationships.

This also means including patients in efforts to reduce disparities and address inequities. Seeking patient input is not only needed for effective efforts, but it reinforces their value and builds trust.