

MARCH 2023

# Maternal Health Equity Data Collection and Sharing

## Operational Guidance

### Why

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The ability to effectively address health disparities and inequities depends on the availability of accurate and actionable data. However, our health care data systems are deeply siloed, full of redundancies, and often fail to accurately capture people's self-identified data on a number of demographic categories critical for understanding the breadth and intensity of maternal care and outcome inequities. Identifying maternal health equity issues, acting upon them, and measuring impacts require the ability to effectively capture, share, and use data to identify disparities in care. The health care industry must advocate for and invest in interoperable information technology (IT) systems for connecting health care, health, and economic and social data that enable seamless interaction, and that facilitate collecting and reporting self-identified data on race, ethnicity, and other demographic elements.

### How

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Several existing resources focus on improving the collection, use, and sharing of Race, Ethnicity, and Language (REL) and Sexual Orientation and Gender Identity (SOGI) data to improve health equity. Health care organizations should consider adopting the steps described below to inform and implement their own strategy for improving the collection and use of this data. These steps are organized by the following actions: 1) Assess the organization's current data collection and infrastructure; 2) Develop an improvement plan; and 3) Implement the plan along with a continuous refinement strategy. For each of these broad actions, there are several key operational components that reflect the complexity of effective data capture and use efforts.

## 1. Assess the Current State of Data Collection

- Organize a team within your organization that includes members with key insights into health equity issues and data collection. This team should include representatives with knowledge or and insights into your organization's activities on:
  - Health equity
  - Patient/member social needs
  - Community engagement/community benefit
  - Patient care/member services (including those responsible for training staff on front office tasks like scheduling and intakes)
  - IT infrastructure and data management
  - Existing community-based resources and referral pathways
- Engage with community members and organizations to identify priority areas, data sources, and opportunities for partnerships. Think broadly about opportunities for meaningful engagement including:
  - Civic groups, religious institutions, community centers, schools
  - Community based organizations, advocacy organizations representing REL/SOGI groups and high priority issues for the community
  - Government organizations (public health, housing, education, transportation, etc.)
- Conduct internal and external baseline assessments.
  - Internal assessment to determine your organization's current ability to capture and effectively use REL/SOGI data.
    - ▶ What is your organization's current process for capturing data?
    - ▶ What are staff and patient/member perceptions on collecting REL/SOGI data?
    - ▶ How complete are your current data?
    - ▶ How accurate are the data you have (do patients agree with how they are categorized in your data sets)?
    - ▶ Does the data you have align with the groups and issues of interest identified in collaboration with community members and organizations?
    - ▶ Does the current data allow your organization to stratify and track care delivery and outcomes across groups of interest?
    - ▶ What would need to change to allow your organization to capture and use data effectively? (Staff training/education, patient/member trust building, IT system investments, improved data sharing arrangements, etc.)

- External assessment to determine outside sources of data and opportunities for partnership.
  - ▶ Are there publicly available sources of data that should be incorporated into your organization's equity strategy?
  - ▶ Are there data sharing or partnership opportunities (other health care organizations, CBOs, schools, public health/government entities, etc.) that would improve your organization's ability to stratify care delivery and quality measures?

## 2. Develop Improvement Plan

- Create a plan for standardizing and improving REL/SOGI data collection. This plan should address three key areas: 1) infrastructure improvement (what changes/investments need to be made to systems), 2) communications/education (how are you going to hear from/work with staff and patients to improve data collection), and 3) assessment/evaluation (how will you put the information gained to use and measure the impact of changes).
  - What data collection tools/surveys/strategies will be used?
    - How do the categories in the tools/surveys align with the populations your organization works with?
    - Will the tool/survey allow for collection of data that are sufficiently granular to support stratification of care delivery and quality measures?
    - What is the strategy for achieving sufficient response rates/sample sizes to support data analysis efforts?
  - What systems will be used for data capture and what improvements need to be made for these systems to operate effectively?
    - Cleaning/validating existing and new data
    - Aligning data elements across surveys
    - Supporting integration of external data sets and exports/data sharing demands
  - How will your organization be coordinating/aligning with other organizations and sources of data?
    - Data integration/alignment processes
    - Data use agreements/business associate arrangements
    - Regular meeting cadence/trust building and maintenance

- Develop strategy for measuring progress on data collection and consider incentive structures for data collection.
  - Develop methodology for measuring baseline and improvements in data capture. Note that these improvement goals will come into play in Step 3 when making decisions on whether to continue to pilot the effort or to expand it.
  - Consider the role of incentives in this plan, including incorporating data capture goals as part of performance metrics for managers and staff (note: this should be done carefully to avoid creating unintended consequences such as pressuring patients who decline to provide information or “guessing” to complete surveys).
  
- Develop patient/member facing materials
  - Articulate the importance of collecting this data including defining the goals and how it will be used to improve care.
  - Develop materials to address concerns with data collection identified by community members during the “current state” assessment. Common concerns include:
    - Lack of clarity on the point of collecting this data
    - Concerns about how data will be used/privacy/discrimination
  - Engage with community members in co-designing materials to ensure they adequately capture concerns and convey information appropriately (plain language, appropriate terminology, translations, etc.)
    - Develop staff training and education materials
  - Articulate the importance of collecting this data including defining the goals and how it will be used to improve care.
  - Address concerns with data collection identified by staff and patients during the “current state” assessment. Common concerns include:
    - Lack of clarity on the point of collecting this data
    - Reluctance/embarrassment to ask personal questions
    - Concerns about patient reactions/how the data will be used
    - Patient frustration with having to provide the same data repeatedly
  - Develop training materials aligned with selected data collection tools (note: patient/member reported data is generally considered best practice rather than having staff complete forms).
    - Guidance on how to engage with patients/members to request data
    - Vignettes/role play opportunities to practice common scenarios and responses
    - Guidance on how to deploy surveys (note: this should include information/research on how the order in which questions are presented impacts responses and data quality).

### 3. Implement and Refine Data Collection, Use, and Sharing Strategies

- Pilot/Roll-out data collection strategy
  - Select a subset of the organization (specific clinics/member groups) to begin implementing the new data collection strategy.
  - Hold regular meetings with staff to monitor to opportunities for improvement. This should include staff with responsibilities for:
    - Health equity
    - Patient/member social needs
    - Community engagement/community benefit
    - Patient care/member services (including those responsible for training staff on front office tasks like scheduling and intakes)
    - IT infrastructure and data management
  - Engage with patients/members to get feedback on their experiences with the data collection strategy.
  - Process feedback and act as needed to refine the data collection strategy.
  - Expand the pilot into a full roll-out once the organization is satisfied with the pilot phase results.
- Analyze, act on, and communicate results of data collection
  - Use newly collected data to identify health equity issues.
  - Leverage data to inform health equity improvement efforts and monitor the impact of any equity initiatives on care delivery and outcomes.
  - Communicate results to staff, key partners, and the community.
    - Develop a strategy for communicating results with staff to build support for initiatives, highlight wins, and build momentum for ongoing work.
    - Create forums for bi-directional communication with key partners and the community on the impacts of health equity initiatives according to your organizations data and to get feedback on community perspectives on any initiatives and results.

## Resources:

- [Race and Ethnicity Data Tool Kit](#) (H-CUP, 2014)
- [Improving Data on Race and Ethnicity: A Roadmap to Measure and Advance Health Equity](#) (Grant Makers in Health, 2021)
- [AHA Disparities Toolkit - How To Use The Data](#) (AHA Institute for Diversity and Health Equity, 2022)
- [Collecting the Data: The Nuts and Bolts](#) (AHA Institute for Diversity and Health Equity, 2022)
- [Improving Collection Of Self-Reported Race & Ethnicity Data](#) (RTI Health Advance, 2022)
- [Improving Patient Race and Ethnicity Data Capture to Address Health Disparities: A Case Study From a Large Urban Health System](#) (National Institutes of Health, 2022)
- [How Mount Sinai Health System Is Building a Foundation for Health Equity](#) (Press Ganey, 2021)
- [Leveraging Your Survey and Analytic Strategy to Support Equity](#) (Press Ganey, 2022)
- [What to Know About Using Data to Improve Diversity, Equity, and Inclusion](#) (Press Ganey, 2022)
- [How To Improve Race, Ethnicity, And Language Data And Disparities Interventions](#) (Health Affairs, 2022)

Find detailed recommendations and more resources at [nationalpartnership.org/raisingthebar](https://nationalpartnership.org/raisingthebar)

### ABOUT HEALTH CARE TRANSFORMATION TASK FORCE

Health Care Transformation Task Force is a unique collaboration of patients, payers, providers, purchasers, and partners working to lead a sweeping transformation of the health care system. By transitioning to value-based models that support the Triple Aim of better health, better care and lower costs, the Task Force is committed to accelerating the transformation to value in health care. To learn more, visit [WWW.HCTTF.ORG](https://www.hcttf.org).



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