



# Measurement of Respectful Care in AIM Statement

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The Alliance for Innovation on Maternal Health's (AIM) seeks to connect, strengthen, and amplify health equity efforts, while filling gaps in literature and practice. AIM recognizes that work towards equity must be executed despite structural and institutional obstacles that hinder progress and reinforce inequitable foundations. The purpose of this document is to detail why efforts to define, document, and collect respectful care measurement data are complex and to identify existing strategies to support meaningful data collection and use to drive health equity and quality improvement efforts.

To integrate respectful care into measurement strategy and data collection, AIM has defined a framework reinforcing a culture of patient safety based on equity. A "5<sup>th</sup> R" of Respectful Care has been added to the previous core AIM Patient Safety Bundles "4 R" structure of Readiness, Recognition, Response, and Reporting & Systems Learning. Each "R" also now has integrated concepts of equity in care, for instance the disaggregation of process and outcome measures by race and ethnicity in Reporting & Systems Learning and Culturally and Linguistically Appropriate Services standards in patient education recommendations.

While care that has been delivered to patients or populations can be measured, the quality of the care delivered cannot be comprehensively measured with quantitative methods. There currently exists no single metric that can assess fundamental culture changes needed to create an optimal environment for respectful, equitable, and supportive patient care. Although the AIM program seeks to integrate respectful care into all clinical practice and care delivery, there is presently no consistent, evidence-informed method to measure this integration.

Patients' perceptions of their health and experiences are essential to providing excellent patient-centered care. There are several patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in various phases of research, development, validation, and endorsement. At least one PREMs questionnaire, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) developed by the Centers for Medicare & Medicaid Services (CMS) and Agency for Healthcare Research Quality (AHRQ), has been endorsed by entities such as the National Quality Forum and Hospital Quality Alliance.

HCAHPS data are publicly reported by CMS and adjusted based on patient factors. These adjustments based on patient factors reflect some of the complexities of PREMs and PROMs data. One such complexity is the variable patient expectations for care that are

based on a multitude of social and structural factors. PREMs and PROMs questionnaires may not be accessible to those who do not speak English as a primary language or who have limited language and literacy proficiency, resulting in selection bias. Questionnaires may be translated into languages other than English to ensure all patients are included in data collection, but literal translations may result in the loss of meaning and intention of the questions. Compounding these barriers, clinicians may not be aware of how to use these qualitative tools accurately and appropriately. These complexities must be considered before using PREMs and PROMs data to evaluate equity in clinical care.

There are also significant barriers to obtaining high quality Race, Ethnicity, and Language (REaL) Data. Barriers to demographic data collection may include concerns about privacy, the legality of collecting this information, options that do not align with patient identity, possible resistance from patients and staff, difficulty recording the data, and uncertainty about whether the data might be useful. REaL data is often incomplete when collected in hospital discharge data or payor data. These inaccuracies may be in part due to historical inequities in medical insurance access and coverage for Black, Indigenous, and people of color (BIPOC) and the collection of data based on observation and not self-reported by patients directly. Incorrect REaL data is disproportionately collected for Hispanic, Native and Indigenous people, and multiracial groups. For instance, Native and Indigenous people are often misrepresented and grouped as multiracial or “other.”

Patients may be hesitant when self-reporting demographic data due to concerns and fear around privacy and discrimination. Patients may not understand why health professionals collect race and ethnicity data. It may be assumed that providing race and ethnicity information may lead to discrimination or misuse of the data, due in part to current and historical abuses such as using reported data to determine immigration status. While collecting race and ethnicity data can provide health care organizations with useful information about their patients, it should be acknowledged that tools to support respectful collection of REaL data are limited and not widely implemented.

As AIM continues to update and create materials to support safe maternal care, we are seeking strategies to include metrics related to respectful care. Equity focused data elements include:

- Screening for social and structural drivers of health using validated tools (Process Measure)
- Curating sets of community resources (Structure Measure)
- Curating printed patient education materials that align with Culturally and Linguistically Cultural Standards (CLAS) (Structure Measure)
- Establishing standardized processes to conduct debriefs with patients after a severe event (Structure Measure.)

Additionally, AIM encourages state teams and participating facilities to disaggregate outcomes and core process measures data by race and ethnicity and, increasingly, other social and structural drivers of health such as payor data. Doing so will better evaluate potential disparities in outcomes and inequities in processes of care, though data may not be reliable in all care settings.

While pursuing opportunities to work with community partners and data scientists who are researching and establishing best-practice standards, AIM seeks to support and collaborate on innovative projects and research on measurement of respectful care. With the above complex context in mind, AIM strives to balance the barriers to equity-related data collection while continuously working toward integration of respectful care into measurement. The AIM program both acknowledges that we are working together in an imperfect system and reaffirms a strong and enduring commitment to building a national, measurable culture of safety, equity, teamwork, and open communication in obstetrical care.

## **References**

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