



May 5, 2023

Caren Ginsberg  
Director, CAHPS and SOPS Program  
Center for Quality Improvement and Patient Safety  
Agency for Healthcare Research and Quality  
5600 Fishers Lane  
Rockville, MD 20857

Re: RFI on Potential CAHPS Survey to Assess Patients' Prenatal and Childbirth Care  
Experience in Ambulatory and Inpatient Settings

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Dear Ms. Ginsberg:

The Health Care Transformation Task Force (HCTTF or Task Force) appreciates the opportunity to provide feedback on Request for Information on the development of a potential CAHPS Survey specifically focused on maternity care, including prenatal care, childbirth care, and post-partum care experiences in ambulatory and inpatient settings.

The Task Force is a multistakeholder consortium that supports accelerating the pace of transforming the delivery system into one that better pays for value. Representing a diverse set of organizations from various segments of the industry – including providers, payers, purchasers, and patient advocacy organizations – we share a common commitment to transform our respective businesses and clinical models to deliver a health system that achieves equitable outcomes through high-quality, affordable person-centered care. We strive to provide a critical mass of policy, operational, and technical support that, when combined with the work being done by the Centers for Medicare and Medicaid Services (CMS) and other public and private stakeholders, can increase the momentum of delivery system transformation.

Since 2020, the Task Force has operated the [Maternal Health Hub](#), with support from the Commonwealth Fund. The Maternal Health Hub Learning Community brings stakeholders together on a monthly basis to share and disseminate strategies to advance value-based care in maternity care. The Learning Community has consistently emphasized the correlation between the community-based model of maternity care (a model that centers care by midwives, birth centers, doulas, and other community-health workers) and improved outcomes, particularly for Black birthing people and newborns. Making the community-based maternity model successful requires a deeper understanding of birthing people's experiences of care – both in terms of clinical processes and outcomes, as well as of respectful care. These sentiments are echoed throughout

The Robert Wood Johnson Foundation's [Raising the Bar for Maternal Health Equity and Excellence](#), a project to which the Health Care Transformation Task Force has been a significant content contributor.

The Task Force appreciates the Agency for Healthcare Research and Quality's (AHRQ) pursuit of developing a CAHPS survey specifically focused on patients' experiences with prenatal, childbirth, and post-partum health care. Our comments focus primarily on the design elements necessary to assess the experience of respectful care that is attentive to a birthing person's preferences through the prenatal, childbirth, and postpartum stages, and to include assessments that relate to and incentivize the use of community-based models of maternity care. Our comments also request that AHRQ provide clarity on how this new survey will interact with the existing portfolio of CAHPS surveys. Several Task Force members have expressed concerns that creating a new CAHPS tool may induce survey fatigue, which subsequently could result in lower-than-ideal response rates.

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### **1. What are the highest priority aspects of patient experiences with prenatal and childbirth health care that should be asked about in a survey?**

The maternal mortality crisis in the United States has a disproportionate impact on Black birthing individuals. This is in large part due to how systemic racism entrenched in our health care system impacts both the clinical and non-clinical factors experienced by birthing people of color. While much needs to be done to address this crisis, measuring patients' experiences – especially regarding perceived respect - with prenatal and childbirth health care is a good place to start. **However, the Task Force strongly recommends that the period of examination be extended to include postpartum care and that the survey clearly distinguish between experiences during prenatal, labor and delivery, and postpartum care, as experiences vary drastically between these times.**

The Task Force has historically supported the inclusion of patient reported outcome and experience measures in payment and quality reporting programs, and deeply supports this effort to extend to maternity care delivery. **The following aspects of care should be prioritized in a patient experience measure:**

#### Access to Community-Based Models of Care

- Did the patient have access to a choice of types of clinical maternity care, including providers (doctor, midwife), birth settings (hospitals, birth center), and labor pain relief (pharmacological and non-pharmacological)?
- Did the patient have the option to access non-clinical maternity services such as doula care? If the patient used a doula, did the patient feel that the doula was welcomed and listened to by the clinical care team?
- Did the patient have 24/7 access to a clinician (e.g., by text or phone) for concerns, and the ability to be seen on the day of urgent concerns?

### Receiving Respectful Care

- Did the patient feel respected by their provider and care team through all interactions in the birthing process (including prenatal, labor and delivery, and postpartum)?
- Did the patient (and family member or other advocate) feel that they were mistreated by the provider, care team, or institution during the birthing process?
- What was the patient's (and family member's or other advocate's) perceived ability to participate in shared decision-making with the provider and care team?
- Were the patient's care preferences respected (e.g. not wanting pain medication or induction of labor)?
- If an unexpected issue arises during labor and delivery, was the patient and (family member or other advocate) informed clearly and were the patient's and family member's/advocate's concerns understood and respected?
- If the patient (and family member or other advocate) raised any health concerns, were they immediately acknowledged and addressed in a satisfactory manner?
- Did the patient have access to FDA approved drugs and devices including postpartum depression and pre-term birth drugs, if desired?

### Experiences with Newborn Care

- What was the birthing person's experience with newborn care? (Note: many items in the Child CAHPS survey do not apply to newborns)
- Did the patient have access to adequate lactation education and support?

### Mental Health Care

- Were mental health screenings performed during the prenatal and postpartum periods?
- Was the patient able to access and receive mental health support through the prenatal, labor and delivery, and postpartum period?

Several tools that support the measurement of the areas listed above are included in response to question five below.

## **2. For which prenatal and childbirth health care settings should measures and/or surveys be developed?**

Currently, there are CAHPS surveys that assess patient experience with certain provider types, two conditions (cancer care and mental health care), facility-based care (emergency department, hospital, outpatient and ambulatory survey, among others), and various health plans. Across all of the CAHPS survey tools, however, there are no questions that explicitly focus on maternity care. Further, an [analysis](#) done by the National Partnership for Women & Families found that the current CAHPS surveys - specifically the outpatient and ambulatory survey and the hospital survey - contain few questions related to pain management (an important domain for birthing individuals) and all provider-level questions refer only to doctors.

**Any survey developed should apply not only to the patient prenatal and birthing experience at clinical institutions (such as inpatient and ambulatory care) but to free-standing birth centers, and to birth centers situated within hospitals as well.** It is important to distinguish and report care received in in-hospital birth centers versus free-standing birth centers, to systematically understand differences in experiences between the two care settings. In terms of provider-level questions, the tool should also include questions that relate to both the care received from a physician and from midwives (across all certification levels) as well as to other types of practitioners (such as physician assistants and nurse practitioners).

### **3. What challenges are there to collecting information about patient experiences with prenatal and childbirth healthcare?**

There are numerous challenges related to collecting this information about patient experiences with prenatal, childbirth, and postpartum health care. The following provides an in-depth dive into some of these issues:

- **Lack of PROMS/PREMS:** There are several challenges that impact the ability to collect accurate, person-level data about a patient's experience with prenatal and childbirth healthcare. Namely, there is a lack of patient reported experience and outcome measures (PREMs and PROMs respectively) available to use in the field. A tool that meaningfully captures the patient's experience will also likely include open-ended questions (which CAHPS historically does not do), which may be less likely to be filled out by the patients. Further, the type of information that should be collected to truly assess the patient's experience could be of a sensitive nature and could result in trauma to the patient by asking them to recount and document a negative experience.
- **Incomplete Demographic Data:** To assess and best use the data collected from PREMs and PROMs to identify any inequities in care received and the accompanying experiences, it is important to collect person-level demographic data. The standard for this data is self-reported by the patient, however, this can be difficult to obtain. In the past, the Task Force has [recommended](#) using imputed data in the interim, as to not prevent data collection efforts from occurring while waiting for gold standard data. Having this data is imperative to analyze and stratify to identify any inequities in experiences of care. The data collected should include race and ethnicity (using the 2024 Office of Management and Budget categories, when they are finalized<sup>1</sup>), sexual orientation and gender identify, disability statuses, socioeconomic status, English proficiency, and more.
- **Language barriers:** Language barriers also pose a challenge to data collection. If there is a lack of translation services available or the surveys are not translated into a person's spoken language, this can result in an inability to collect information about their experience. It is important to offer the survey in multiple languages (for any ethnicity that makes up at least five percent of the population).

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<sup>1</sup> <https://www.federalregister.gov/documents/2023/01/27/2023-01635/initial-proposals-for-updating-ombs-race-and-ethnicity-statistical-standards>

- Potential Diminishing Returns Due to Existing Surveys: While the need for a maternity CAHPS is great, it must be acknowledged that there are a number of other patient-reported experience surveys in the field, some of which are often not filled out completely due to their length. AHRQ should clarify how it plans to coordinate use of the maternity CAHPS tool such that it will not be “lost” among other CAHPS surveys, and other maternity surveys.
- Lack of Trust with the Medical System: Perhaps the most significant challenge is the lack of trust that historically underserved and minority populations have with the health care system. This stems from decades of mistreatment and can result in patients not feeling comfortable reporting on their full experience with the care team and care delivered. This is a significant factor that must be addressed in the design of how a maternity CAHPS tool would be fielded. The Task Force urges AHRQ to, in parallel with measure design, consider the investments that will be needed to involve and employ trusted members of the community (such as community health workers) to help collect patient experiences with care in a respectful and thoughtful manner. This will require addressing current prohibitions on proxy respondents and on staff members assisting patients with the survey. Further, the survey should open with a disclaimer about how the data will be used in a confidential way to help prioritize efforts to improve patient care.

In relation to medical system mistrust, CAHPS surveys collect data about the patient’s experience, yet there is no standardized infrastructure in place to ensure that an organization follows up and acts upon any negative experiences reported by the patient. If an individual reports an experience of discrimination or mistreatment and there is no follow up, it may result in more mistrust of the system. Therefore, there should be a protocol for steps the organization should take to mitigate the occurrence of a similar experience in the future, and to ensure that the patient who experienced the event has needed support services. This is another area for AHRQ to consider in future work, in collaboration with the CMS.

#### **4. What actions or approaches would facilitate the collection of information about the experience of patients with prenatal and childbirth healthcare?**

Currently, most CAHPS surveys are administered through four approved modes: 1) mail only; 2) telephone only; 3) mixed (mail followed by telephone); and, 4) active interactive voice response. These are effective methods of collecting information from patients, however, more can be done to ensure all patients are reached in a way that does not create additional burden on new parents.

**Moving forward, a web-based option to complete the survey should be available to all patients.** The FY 2024 Inpatient Proposed Payment Systems Proposed Rule proposes a web-based survey option for HCAHPS; the Task Force supports alignment here. This could be distributed through the patient’s care portal, via a link included in the mail outreach that can be typed in, or through SMS texting technology. This should be used in tandem with the other

methods, as some individuals may not have access to a smartphone for SMS texting or to a device that has internet connection.

While more difficult to implement, another method of collecting the information could be to conduct the survey in person, using a trusted member of the community to discuss the individual's experience. If this method is utilized, this could include narrative responses that provide more information than traditional CAHPS fixed response choices. Acknowledging that open-ended questions may not be able to be scored in the same way as fixed-response questions, the Task Force suggests these questions be included in a supplemental tool and be used to support quality improvement activities, rather than for public reporting or payment. This open-ended discussion of experiences should be used in tandem with the other modes of survey administration, and only used when this is the patient's preference. Given that some aspects of the care experience (such as experiencing discrimination or bias) can be sensitive and difficult to discuss, it is important a trusted and respected member of the care team is available to hear the responses. This could be a community health worker, doula, or a third-party community organization that is brought in for the sole purpose of administering the surveys in person.

**The Task Force urges AHRQ to consider publicly reporting the scores on the maternity care survey.** Results from other CAHPS surveys, such as the HCAHPS survey, are publicly reported on a quarterly basis to allow for comparisons across hospitals by consumers. Informing consumers that their responses could help other patients choose the best care available to them may drive survey uptake.

#### **5. Which survey measures that assess prenatal and/or childbirth care experiences are currently being used?**

The [Birth Place Lab](#) in British Columbia, Canada, has created several measures that assess the non-clinical factors of a patient's experience with prenatal and child birth care. The tools are unique in their ability to assess the birthing person's experience with autonomy, respect, and mistreatment:

- The [Mothers Autonomy in Decision Making \(MADM\) Scale](#) assesses a birthing individual's perceived autonomy in their maternity care experience. The scale analyzes a birthing individual's ability to lead the decision making; if they are given enough time to consider their options; and if their care choices are respected after the decision is made. The questions are answered on a scale of one to six, with six strongly agreeing that a patient's autonomy was respected in the interaction. The sum of all the answers correlates with a developed scale; those with a lower total sum experienced less autonomy in their birthing experience, whereas those with a higher score experienced greater autonomy.
- The [Mothers on Respect \(MORi\) index](#) evaluates the nature of respectful patient-provider interactions and their impact on a person's comfort, behavior, and perceptions of racism and discrimination. The scale focuses on three domains: (1) a birthing individual's sense of autonomy and comfort when accepting or declining care options; (2) evidence of the birthing individual modifying their behavior as a result of fear of anticipated disrespect; and (3) perceived differential treatment as a result of a non-modifiable socio-demographic

factor (race, ethnicity, sexual orientation, health insurance, etc.). The three categories are combined into one final score with a higher score indicating more respectful care.

- The [Mistreatment \(MIST\) Index](#) is a set of patient-designed indicators of mistreatment that align with the seven dimensions of mistreatment identified in the Bohren typology<sup>2</sup>. The seven components assessed are physical abuse, sexual abuse, stigma and discrimination, failure to meet professional standards of care, poor rapport between birthing individuals and providers, and poor conditions and constraints presented by the health system. This tool does not score responses; rather it provides a check box for individuals to mark if they feel mistreated along any of these seven dimensions. Used in tandem with the two tools described above, it can provide insight into why a patient may have recorded an occurrence of mistreatment. In using this tool, appropriate standards should be in place so that if a patient marks the questionnaire affirmatively, they receive timely and respectful follow up that investigates the incidence.

The measures mentioned above have great potential to impact the maternal quality measurement enterprise. If adopted at a widespread level, they can be used to not only assess the experience of a patient, but to compare the performance of providers and health systems across health care organizations.

The Task Force posits that creating a unique survey for maternity care is the gold standard. If AHRQ does not pursue the creation of a unique survey, the Task Force urges AHRQ to explore integrating questions into the existing inpatient CAHPS surveys that explicitly address prenatal, childbirth, and postpartum care experiences. At a minimum, these questions should be included in both the HCAHPS and OAS CAHPS surveys. Further, while CAHPS assesses the experience with providers, we urge AHRQ and CMS to integrate maternity specific questions into existing health plan CAHPS surveys to assess the patient experience with their health plans when receiving maternity care.

Finally, the Task Force would be remiss to not highlight the numerous efforts already underway or completed in the field to improve maternity care, many of which strive to measure the current experience of care for birthing individuals. We urge AHRQ to review the following efforts to ensure any new survey is additive to current efforts.

- NBEC Birth Equity through Accountability Measurement Project (in progress)
- [SACRED Birth Survey](#)
- [CMQCC Quality Improvement Initiatives](#)
- [Listening to Mothers Survey](#)

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The Task Force appreciates the opportunity to respond to this RFI. Please contact HCTTF Senior Director Tanya Alteras ([tanya.alteras@hcttf.org](mailto:tanya.alteras@hcttf.org)) with any questions.

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<sup>2</sup> <https://pubmed.ncbi.nlm.nih.gov/26126110/>

Sincerely,

*Jeff Micklos*

Jeff Micklos

Executive Director

**TASK FORCE MEMBERS:** Aetna • agilon health • Aledade • American Academy of Family Physicians • American Heart Association • ApolloMed • Atrius Health • Blue Cross Blue Shield of Massachusetts • Blue Cross Blue Shield of Michigan • Blue Cross Blue Shield of North Carolina • Blue Shield of California • Cambia Health Solutions • Clarify Health • Cleveland Clinic • Community Catalyst • Connections Health Solutions • Curana Health • Elevance Health • Evolent Health • Families USA • Heritage Provider Network • Honest Medical Group • Innovaccer • Kaiser Permanente • Mark McClellan • MedStar Health • Mental Health America • National Partnership for Women & Families • National Patient Advocate Foundation • OPN Healthcare • Policy Center for Maternal Mental Health • Premier • PSW • Sentara Healthcare • Signify Health • Sun River Health • Trinity Health • Washington State Health Care Authority • UAW Retiree Medical Benefits Trust