

July 30, 2024

Micky Tripathi, PhD, MPP
National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
330 C St SW, Floor 7
Washington, DC 20201

RE: Feedback on the USCDI+ Maternal Health Draft Dataset

Dear Dr. Tripathi,

[United States of Care](#) (USofCare) is pleased to submit the following comments on the United States Core Data for Interoperability+ (USCDI+) Maternal Health (MH) [draft dataset](#).

USofCare is a nonpartisan, nonprofit organization working to ensure everyone has access to quality, affordable health care regardless of health status, social need, or income. We drive change at the state and federal level in partnership with everyday people, business leaders, health care innovators, fellow advocates, and policymakers. Together, we advocate for [new solutions](#) to tackle our shared health care challenges — solutions that people of every demographic tell us will bring them peace of mind and make a positive impact on their lives. Through [our work](#) in states, we are able to identify the unique perspectives of people on the ground and amplify them at both state and federal levels. Where possible, we uplift voices of real people engaging with the health care system whose [perspectives](#) shape our advocacy work.

Over the past two years, USofCare has conducted robust [listening research and different analyses on maternal health](#) to understand the critical gaps and failures experienced and the elements needed to ensure that everyone has a joyful, safe, and supported maternal health journey. Throughout our comments in response to the USCDI+ MH draft dataset, we include select quotes from our listening work with women and pregnant people,¹ highlighting their personal experiences and identifying gaps in maternal health care. Equipped with this knowledge, USofCare has reviewed the USCDI+ MH draft dataset and has provided the responses to the following questions raised by the Office of the National Coordinator (ONC):

- Does the USCDI+ MH dataset contain all core data elements important for maternal health services and outcomes, and linking maternal health to infant/child health?
- Are the data elements and descriptions clear? What clarifications or updates are recommended?
- Are there additional data elements or screenings that should be included to provide insight into health equity considerations and outcomes?
- What data elements are available or should be included to understand equitable patient experience and respectful maternal health care?
- Are there data elements in the USCDI+ Maternal Health dataset that might be too difficult to capture and/or share?

¹ **Note:** USofCare utilizes the term “women” within our comment letters when referring to our research, as all listening work participants identified as women. USofCare acknowledges and respects that not all people who go through pregnancy identify as women.

- Are additional clarifications or considerations needed to support the collection of data elements across multiple visit types and care settings (e.g., prenatal ambulatory, antepartum, intrapartum, postpartum, post-natal ambulatory visits)?
- Are there any high-priority data elements missing from the dataset?
- Are there any data classes and/or elements in the dataset that commonly present data quality issues when obtained? What information is the most challenging to obtain and why?

Does the USCDI+ MH dataset contain all core data elements important for maternal health services and outcomes, and linking maternal health to infant/child health?

The USCDI+ MH dataset contains many core data elements necessary for maternal health services and outcomes, but does not fully encompass critical aspects of the postpartum period. The postpartum period is a crucial phase, as it constitutes a significant portion of the maternal care journey – defined as one year after delivery – and most maternal deaths [occur](#) during this time. It is why, as an advocacy organization focused on maternal health, we deliberately discuss the full maternal health journey as inclusive of 100 weeks. We encourage policymakers and researchers to encompass the full postpartum experience in datasets in recognition that a person’s maternal health journey must capture the comprehensive experiences long after delivery and birth. Despite its significance, there are limited postpartum measures in place within the dataset. With this in mind, USofCare encourages ONC to evaluate additional measures inclusive of the postpartum experience.

*“When you were pregnant, they were supporting you to make sure you are fine, healthy, and good. Once the baby came it was [all about] the baby. ‘How is the baby doing?’ and not the mom. But I still felt that I needed that support.”
~ Black woman in the Northeast*

Examining and capturing data on people’s experiences is essential, especially during the postpartum period. Maternal health data has typically focused on clinical outcomes, but this quantitative data does not adequately capture the full spectrum of people’s birthing experiences. USofCare’s listening work reveals that many women have had less-than-ideal pregnancy, birthing, and postpartum experiences, even if they did not lead to direct adverse health outcomes.

Collecting patient-reported data on their pregnancy, birthing, and postpartum experiences paints a better picture of maternal health, and is a step towards ensuring greater accountability and better care. Recognizing the importance of the patient experience, the Agency for Healthcare Research and Quality (AHRQ) is [developing a CAHPS \(Consumer Assessment of Healthcare Providers and Systems\) survey for maternal care](#) to assess patients’ prenatal and childbirth experiences. Because of this, **USofCare recommends that ONC add postpartum care measures and experience measures to the USCDI+ MH dataset to capture the holistic experiences of women and the continuum of the maternal health journey.**

Are the data elements and descriptions clear? What clarifications or updates are recommended?

The data elements and descriptions within the USCDI+ MH dataset are generally clear. **However, significant clarification and updates are needed during the postpartum period to accurately reflect the scope of maternal health care.** The “Postpartum Indicator” data element defines postpartum as “giving birth less than 12 weeks ago,” which does not fully capture the postpartum period which extends far beyond 12 weeks. The [American Medical Association](#) and the [American College of Obstetricians and Gynecologists](#) support expanding Medicaid coverage from 60 days to 12 months postpartum in recognition that health challenges from pregnancy and childbirth often persist up to a year after delivery. Furthermore, 47 state Medicaid programs have extended postpartum coverage to one year. **We recommend that ONC update the definition of the “Postpartum Indicator” data element to one year following birth to align with best practices and recent policy changes.**

Are there additional data elements or screenings that should be included to provide insight into health equity considerations and outcomes?

Our listening work highlights the importance of social determinants of health (SDOH). Women shared that they encountered different barriers to care, including high health care costs, transportation challenges, limited social support, and [a lack of culturally competent care](#), all of which significantly impacted their ability to access care, their maternal care experience, and their health outcomes. For example, one research participant shared the hardships she experienced in her maternal health care journey, highlighting the types of services and resources outside of the four walls of a health care setting that can have an enormous impact on a person seeking maternal health services.

*“[We need] health care, food, more jobs. Anything for the kids to do. Closer health care, and doctors.”
~ Black woman in South Carolina*

Additional data elements and screenings related to SDOH can enhance the USCDI+ MH dataset to provide insight into health equity considerations and outcomes. In particular, breaking out and specifying actual social determinants and drivers will make the data more actionable. For example, addressing housing insecurity, food insecurity, and transportation barriers requires distinct approaches. Specifying these social driver elements can guide targeted interventions and linkages with social and community-based services. This approach aligns with the [White House Blueprint for Addressing the Maternal Health Crisis](#), emphasizing the need to collect more and better data on SDOH to improve maternal health outcomes.

We recommend that the USCDI+ MH dataset **incorporate additional data elements for specific categories of social determinants** (i.e., transportation, food, housing, etc.) to drive actionable interventions and improve outcomes for all mothers, especially those from marginalized communities.

What data elements are available or should be included to understand equitable patient experience and respectful maternal health care?

Our listening work revealed that many Black women and women of color [experience](#) racism, discrimination, and dismissive care during their maternal care journey, which negatively impacts their pregnancy and postpartum experiences. Furthermore, many women explained that they felt their health care visits were transactional, that they did not receive enough

information, and that health care providers made assumptions that impacted their ability to receive tailored care.

“I have talked to other women that are non-African American and their experience is totally different from mine...I just feel sometimes there is a stigma or a judgment that I face because of the color of my skin.”

~ Black woman in the Northeast

It is essential to include data elements that capture the nuances of patient interactions and outcomes to drive equitable and patient-centered care. A patient-centered care approach respects individual preferences, needs, and values, and ensures that patient values guide clinical decisions. Patient-reported data elements should include:

Experiences of Racism & Discrimination

Studies have shown that [Black women](#) and other women of color in hospital settings often feel [disrespected and ignored during childbirth](#).

I believe I didn't get the best care after delivering the baby at [the] hospital as a Black woman. And also, they didn't really try their best for a vaginal birth. I could not advocate for myself because I was alone and [a] first time mom and nervous.”

~ Black woman in Michigan with Marketplace coverage

Satisfaction with Prenatal, Delivery, & Postpartum Care

Even if women have good clinical outcomes, that does not necessarily mean they are receiving the care and support that meets their needs.

“Everything else was pretty transactional. Provided me with the very necessary information, answered my questions, and on my day I went...I didn't feel like they took the time to get to know me and what makes me, uniquely me. It was kind of textbook information and just on what they saw. They made assumptions about me before they even began to treat me.”

~ Black woman in North Carolina with employer-sponsored coverage

A patient-centered care model is associated with [increased patient satisfaction, trust in the provider, and better mental and physical outcomes](#) in the postpartum period. By collecting and measuring [patient-reported outcomes and experiences with discrimination](#), health care systems can set goals for high-quality care and track progress for individual providers and care teams. **We recommend that ONC incorporate the patient-reported data elements above to enhance health outcomes and promote equitable patient experiences.**

Are there data elements in the USCDI+ Maternal Health dataset that might be too difficult to capture and/or share?

While SDOH data is commonly captured in health care settings, there are [several challenges](#) to capturing this information, including a lack of standard data formats and insufficient training and education on capturing, collecting, and coding the data.

Are additional clarifications or considerations needed to support the collection of data elements across multiple visit types and care settings (e.g., prenatal ambulatory, antepartum, intrapartum, postpartum, post-natal ambulatory visits)?

Accountability

While the USCDI+ MH dataset includes measures to be collected, we are concerned that data collection will not equate to accountability in patient follow-up care. For example, merely performing anxiety and depression screenings is insufficient without adequate and appropriate follow-up. According to the [Healthcare Effectiveness Data and Information Set \(HEDIS\)](#) measurement year 2022, nearly 35% of women who screened positive for postpartum depression did not receive follow-up care. **We recommend that health plans and Medicaid implement incentives or that USCDI+ adds data measures to track follow-up or referrals and ensure people receive the care they need.**

Data Interoperability

During her perinatal period, a woman may interact with a primary care provider, obstetrician, midwife, mental health provider, and her child's pediatrician. For example, a new mother may be screened for anxiety and depression at her baby's well-child visits, but the screening results aren't shared with her primary care provider. **Given the siloing of data in the health care system, we recommend providers be required to share data to ensure that women receive patient-centered care and don't fall through the administrative cracks of the health care system.** Stakeholders in the health care field should prioritize ease of data exchange by championing [national interoperability](#).

Missing Data

Maternal health datasets only capture patient information for women with regular access to care. As a result, we do not have much data for those who may be delaying or skipping care until childbirth. Women with less than a high school education, women living in rural areas, and women who are Black, Hispanic, or American Indian/Alaska Native are [disproportionately more likely](#) to delay initiation of prenatal care and to have poor birth outcomes. **We recommend that ONC consider strategies to collect more robust data from patients who are unable to access care regularly and who are historically underrepresented in maternal health research.**

Are there any high-priority data elements missing from the dataset?

The "Postpartum Summary Note" data element mentions the inclusion of intimate partner violence (IPV) screening, but this screening is not listed as an extra data element (unlike the depression screen). IPV is the most common form of violence against women, and IPV experienced during the perinatal period is associated with [poor outcomes](#) for both the mother and baby. Studies show that the perinatal period [increases the likelihood](#) of experiencing violence, particularly for younger women and non-Hispanic Black females. Furthermore, homicide is a [leading cause of death](#) during pregnancy and the postpartum period in the United States. **Therefore, we recommend the inclusion of an "Intimate Partner Violence Screen" data element.**

Are there any data classes and/or elements in the dataset that commonly present data quality issues when obtained? What information is the most challenging to obtain and why?

Postpartum Data Classes

Data quality is at risk in postpartum data classes due to the limited number of postpartum care visits and a lack of quality care. For example, most women are likely to have just one or two postpartum visits compared to eight to 14 prenatal visits. [Studies](#) show that many women do not attend any postpartum visits. Furthermore, there is a data quality issue given that many postpartum visits are [not comprehensive](#), meaning that they do not cover every data element outlined in clinical guidelines.

Anxiety Screen & Depression Screen Data Elements

Unfortunately, the anxiety and depression screens present several data quality issues when obtained. First, standard screening tools such as the Edinburgh Postnatal Depression Scale and the Perinatal Anxiety Screening Scale were developed using white mothers as research participants, resulting in tools that are [less applicable](#) to Black mothers and mothers of color. Additionally, research has found that racial and ethnic groups [talk about and experience](#) mental health conditions differently, which may delay or prevent the recognition of maternal mental health conditions and hinder the necessary care and treatment women critically need. Second, new mothers may not answer the questions in an anxiety or depression screen honestly for [fear of repercussions](#), such as being reported to child protective services or being treated poorly for their racial or ethnic identity. Fear of child protective services involvement is not unfounded, as one study [demonstrates](#) that the rate of CPS reports is 2.6x as likely for a new mother with a reported mental health disorder than a new mother without a mental health disorder.

Conclusion

Thank you for the opportunity to respond to this feedback request, which builds towards USofCare's goal of ensuring that everyone has a joyful, safe, and supported pregnancy and postpartum experience. Please contact Annie Yu, Policy Innovation Manager, at ayu@usofcare.org, with any questions.

Sincerely,



Lisa Hunter (she/her)

Senior Director for Policy & External Affairs
United States of Care