

# Life Course Indicator: Experiences of Race-Based Discrimination or Racism among Women

## The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the [W.K. Kellogg Foundation](#).

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

### Basic Indicator Information

**Name of indicator:** Experiences of Race-Based Discrimination or Racism among Women (LC-13)

**Brief description:** Percent of women who experienced discrimination right before or during pregnancy.

**Indicator category:** Discrimination and Segregation

**Indicator domain:** Risk/Outcome

**Numerator:** Number of women who answer Yes to the question “During the 12 months before your new baby was born, did you feel emotionally upset (for example, angry, sad or frustrated) as a result of how you were treated based on your race?”

**Denominator:** Total number of women who recently had a live birth

**Potential modifiers:** race, ethnicity, sex, age, SES, geographic location

**Data source:** Pregnancy Risk Assessment Monitoring System (PRAMS)

**Notes on calculation:** Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

**Similar measures in other indicator sets:** None

## Life Course Criteria

### **Introduction**

In their seminal paper on the life course perspective, Lu and Halfon posit that a portion of the racial and ethnic disparities in birth outcomes in the United States are attributable to the experience of discrimination on the basis of race (Lu and Halfon 2003). This assertion is bolstered by studies that have demonstrated associations between maternal perception of exposure to discrimination during pregnancy and giving birth to a very low birth weight infant, among low income African American women (Collins et al 2000) and experiences of discrimination during prenatal care among African American women with limited incomes (Salm Ward et al 2012). A review of studies demonstrated associations between perceptions of discrimination and poor birth outcomes, including preterm birth, low birth weight, and very low birth weight (Giurgescu 2011). There is evidence that race-based discrimination impacts not only a woman's health and her birth outcomes, but also impacts birth outcomes across generations. Studies focused primarily on birth weight have demonstrated that a mother who was born low birth weight is more likely to have a child born low birth weight (Emmanuel 1986). The Barker hypothesis demonstrated how the fetal environment (including the experience of stress by the mother during pregnancy) impacts the health of that adult, including coronary artery disease and hypertension risk (Barker et al 1993). Further, the impact of maternal weight on the weight of her offspring is independent of factors such as receipt of adequate prenatal care (Coutinho et al 1997, Collins et al 2003).

Finally, the concept of "weathering," or early health deterioration among African American women, as introduced and explored by Geronimus (1992 and 1996), explicitly points to the cumulative nature of the impact of discrimination on the health of African American women; "This hypothesis suggests that maternal age be reexamined as being not only a developmental indicator but also a reflection of the ways in which social inequality, racial discrimination, or race bias in exposures to psychosocial or environmental hazards may, on a population level, affect differentially the health of black vs. white women who will become mothers, not only in absolute terms, but also interactively with each other and cumulatively as women age" (Geronimus 1996).

For the purposes of this discussion, the phrases "perceived discrimination" and "experience of discrimination" will be treated as having the same meaning, which is to say that a person is reporting their lived experiences with discrimination; no self-report health survey is able to assess the intent of those inflicting the discrimination.

### **Implications for equity**

A key factor in exploring issues of discrimination is to use a clear definition of racism. Krieger defines racism as, "Institutional and individual practices that create and reinforce oppressive systems of race relations whereby people and institutions engaging in discrimination adversely restrict, by judgment and action, the lives of those against whom they discriminate" (Krieger 2003). This definition is useful because it calls out actions of the individual as well as the policies that contribute to system level institutionalized racism. A further examination of the levels of racism put forth by Jones describes three levels, which include the above-described institutionalized and personally mediated racism, and introduces a third level, internalized racism, which she defines as, "Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth (Jones 2000)." All three levels of racism contribute to poor health outcomes.

There are many socioeconomic factors that impact the health of women in the United States, including education, income, and health insurance status (Ross et al 2012, Jones et al 2002). There is evidence that women of all racial/ethnic groups have worse health outcomes than their male counterparts (Read and Gorman 2006). Further, women of color have worse health outcomes than their white counterparts (Read and Gorman 2006). All of this information points to a need to focus particularly on the experiences of women as they seek and receive health services.

Pregnancy is a critical and sensitive period in the life course of a woman; her life experiences prior to and during pregnancy have the potential to directly impact the health of her children and her children's children, as well as the overall health and well-being of her family. Despite decades of work to reduce disparities in birth outcomes, two- and three-fold differences in infant mortality, low birth weight, preterm birth, and other health outcomes persist. As proposed by Lu and Halfon (2003), if the persistent disparity in outcomes is at least in part attributable to the impact of racism experienced by African Americans over generations, it is essential to monitor women's experiences of discrimination immediately before and during pregnancy, as well as the experiences of discrimination when receiving health care for all adults and the

experiences of racism reported by children. These three life course indicators provide the field of MCH and our partners with a powerful picture of the pervasiveness of experiences of racism, which is the first step in being able to design strategies to reverse racism and restore equity.

Racism in health care can occur at the physician-patient level and at the health care system level including institutionalized racism. As outlined in the Institute of Medicine *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, racial and ethnic disparities are consistently present across a wide array of diseases, and the quality of health care services received varies by race and ethnicity, with African Americans and Hispanic/Latino Americans receiving poorer quality care than white Americans (Smedley et al 2002). Schulman et al found that the race and sex of the patient affected physician's decisions about recommending cardiac catheterization even after adjusting for symptoms, clinical characteristics, and physician estimates of the probability of coronary disease; black females were least likely to be referred for cardiac catheterization compared with white males (Schulman et al 1999).

At least one factor that underlies the issue of discrimination in health care is what some call a legacy of racism in health care in the United States that has contributed to distrust in the health care system. The Tuskegee Syphilis Study, in which researchers from the government (the U.S. Public Health Service) withheld treatment from 400 black men with syphilis in Alabama, has been well described. Kennedy et al explore the historical context that contributes to distrust of the health care system, which includes experiences with slavery and segregation, feelings of being used as experimental guinea pigs, and belief of being treated differently from white patients (Kennedy et al 2007). Part of achieving equity is not just to provide equal access to health care, but to ensure that the access is equitable, meaning that it meets the needs of the person receiving it.

An analysis of North Carolina PRAMS data from 2006-2008 found that 16 percent of African American mothers reported emotional upset due to perceived racism compared with only eight percent of white mothers (NC PRAMS fact sheet 2011). Oregon PRAMS conducted a similar analysis with some notable differences. There is very little racial/ethnic diversity in the Oregon population, and therefore, the PRAMS question assesses whether women felt they had ever been treated differently by health care providers during prenatal care, labor, or delivery because of their race, culture, ability to speak or understand English, age, insurance status, neighborhood in which they lived, religious beliefs, sexual orientation or lifestyle, marital status, or desire to have an out-of-hospital birth (DeMarco et al 2008). Nearly one in five Oregon mothers reported discrimination during prenatal care, labor, or delivery, and the most common perceived discrimination was on the basis of age or insurance status. This study illustrates that perceived discrimination, while primarily focused on race, can be related to many other social and economic characteristics; when a woman has more than one of these characteristics (low income, young age, minority race/ethnicity), her chances of experiencing some sort of discrimination may increase.

### **Public health impact**

The consequences of experiencing discrimination in health care settings are multifaceted. The sections above addressed the biological consequences for a woman, her family, and potentially for generations, as transmitted through accumulated stress and poor birth outcomes. However, if racism is reduced or eliminated, there are immediate consequences beyond the long-term outcomes, including a potential reduction in the dissatisfaction with the care received (Bird et al 2004), an increase in the likelihood that a woman will continue to seek care (Blanchard and Lurie 2004), and an increase in seeking and receiving preventive health services (Trivedi and Ayanian 2006). In addition to care satisfaction and care seeking behavior, reducing racism may result in improvement in health behaviors and outcomes; for example, studies have found that women who experience racism also are more likely to contract HIV (Newman et al 2008), to smoke (Purnell et al 2012) and be depressed (Ertel et al 2012).

### **Leverage or realign resources**

Many public health agencies have begun to implement principles of cultural competence. Betancourt et al defined a framework for cultural competence that addresses barriers to appropriate care at the organizational (leadership/workforce), structural (processes of care), and clinical (provider-patient encounter) levels (Betancourt et al 2003). Experiences of racism occur at all levels of patient interaction, from receptionist to surgeon, and therefore work to ensure culturally and linguistically appropriate care must extend beyond just the provider-patient relationship. All members of facility or practice staff should be included in training and implementation of cultural competence. Health care systems

also can reach out to community services that work to eliminate racism and engage in new partnerships to develop programs for their institution.

Efforts to address the experiences of discrimination in health care and health research have utilized the concepts of “undoing racism” and community-based participatory research (CBPR) to begin the conversations around racism and begin to establish trust (PISAB 2013, Yonas et al 2006). It should be noted that efforts to “un-do” racism and achieve equity require more than a short-term training and will include an authentic partnership between care providers, public health, and communities, including community leaders, to make strides toward improving experiences of care and equity in health care in the long term.

### ***Predict an individual’s health and wellness and/or that of their offspring***

Previously discussed in the context of health equity are the impacts and effects of race-based discrimination on a woman’s health and her birth outcomes, the cumulative nature of the impact of discrimination, and the concept of “weathering.” An exploratory study utilizing focus groups of African American women found that women experienced racism throughout the life course, that childhood experiences of racism seemed to have enduring effects, and that women experienced racism directly, through the experiences of their children, and in all three forms outlined above (interpersonal, institutional and internalized) (Nuru-Jeter et al 2009).

In a study of the perceptions of racism among African American mothers participating in a pre-paid health plan, mothers were most concerned about their children being subject to institutionalized racism, such as being harmed or harassed by the police or getting stopped in a predominantly white neighborhood, and respondents who reported high levels of perceived racism also reported greater concern for their children (Vines and Baird 2009).

The experience of racism in health care is further compounded by experience of racism in other areas of life including residential segregation, which also is a life course indicator. According to Williams & Collins (2001), segregation is a main source of racial and ethnic differences in socioeconomic status (SES) by determining equitable access to education and employment opportunities, as well as environmental conditions that may impact health (e.g., health care access, healthy food or physical activity environments), all of which have implications for racial and ethnic differences in health.

## **Data Criteria**

### ***Data availability***

PRAMS was initiated in 1987 and is an ongoing population-based surveillance system designed to identify and monitor selected maternal experiences and behaviors that occur before and during pregnancy and during the child’s early infancy. Forty states and New York City currently participate in PRAMS, representing approximately 78 percent of all U.S. live births. Six other states previously participated. The CDC maintains a combined dataset with information from all participating PRAMS states, which represents approximately 87 percent of all live births in the United States. CPONDER is a Web-based query system created to access data collected through PRAMS surveys.

The length of time between an event and entry into the sampling frame is typically two to six months. Because PRAMS data are weighted to the final birth file, there is a data availability lag between the close of a calendar year and access to the final PRAMS dataset. As of July 2013, the most current year of data available in CPONDER was 2008. Although the 40 states and one city that participate in PRAMS have access to their own state data, only states where the minimum response rate has been met are included in CPONDER. For 2000-2006, this required response rate was 70 percent, and for 2007-08 it was 65 percent. The required response rate may limit the availability of a “national” estimate through CPONDER, but states with PRAMS are encouraged to use their own data whenever possible. The PRAMS survey consists of core questions that all states must include and standard, pilot-tested questions that states may choose to add. In addition, PRAMS allows states to design and add their own questions, and the state is responsible for completing question testing before the question can be included.

Although the question associated with this indicator is part of the standard list of questions that states can add to their PRAMS surveys, this indicator is not available for all states. This question was asked in Phase Five of the survey (2004-2008) for: North Carolina, New York City, Tennessee, Washington and Wisconsin; in Phase Six of the survey (2009-2011)

by: Michigan, North Carolina, Tennessee, and Wisconsin. Currently, there are nine sites using this question in Phase 7 of PRAMS (2012- present): Wisconsin, Ohio, Virginia, Louisiana, Minnesota, North Carolina, Utah, New York City and Iowa.

### **Data quality**

PRAMS is a mixed-mode surveillance system that combines mail and telephone surveillance. Each year's sample is weighted to represent all births that meet the inclusion criteria before reporting. Unlike many health surveys, the PRAMS project has a wealth of information from the birth certificate on those who do not respond by either mode of contact, and therefore weighting can be effective at minimizing differences between respondents and non-respondents.

Since the PRAMS survey is completed retrospectively by a woman two to six months after her birth outcome, some bias may occur due to self-reporting and recall. PRAMS is sampled from live births only, so the data do not include information on other pregnancy outcomes such as abortions, miscarriages, or stillbirths; the data do include responses from women who have experienced an infant death. PRAMS is sampled among singleton, twin, and triplet births, and therefore it is not representative of higher order births.

This measure is unique in its availability because no other data source captures this information specifically for women who have had a live birth. However, this is a single question that attempts to measure a very complex construct, and there have been no studies to date that have validated the information collected.

### **Simplicity of indicator**

This indicator is relatively simple to calculate across geographic regions, where available, once the data has been downloaded and available. The indicator is simple to explain and use.

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