Introduction

WEIGHING THE FUTURE

You are pregnant.

You are pregnant, and as your mom explains, "heavy set"; or as your cousin says, *nalgona*; or as the tags on your jeans read, "curvy"; or as your doctor terms it "obese"; or as you say, fat.

You are pregnant, fat, and you decide to participate in a clinical trial on diet and exercise because your doctor suggested it might help you, and because someone in the waiting room of your prenatal clinic came up to you and gave you some brochures talking about how weight and diet can affect your pregnancy and your child's health. You don't want what happened last time to happen again, so you call up the number on the brochure, and the woman on the phone schedules your first clinical trial appointment.

You go to your usual prenatal clinic, and instead of meeting with your doctor or nurse, you meet a staff member from the trial. The first thing she does is tell you to "step on the scale, please." She explains that she needs to weigh you twice for accurate measurements. You don't hesitate for a second because you're used to stepping on the scale for every single medical appointment.

The woman hands you some paperwork and asks you to fill out a questionnaire. The questions are: Do you ever feel like harming yourself? Have

you ever binged or skipped a meal to control your weight? Do you feel less enthusiastic about your usual activities?

You cringe, and your body tightens up.

You're thinking of your last pregnancy and the loss. You keep sifting through the papers, and the woman starts talking again: "The reason we are doing this trial is to help women gain a healthy amount of weight during pregnancy. Gaining too much weight can put a woman at risk for GDM [gestational diabetes mellitus], increased weight retention, and health problems *in the future* for both mother and baby."

You don't pay close attention to the description of the trial because it sounds similar to what you've already heard.

You finish the mental health survey, but you tell the woman that the questions are weird because you're grieving. How are you supposed to answer these questions when you're grieving, pregnant, and feel tired all the time?

The woman apologizes profusely and thanks you for coming to the appointment.

Then she says, "This is an opportunity to be involved in cutting edge research that's part of a larger consortium across the whole country . . . to be involved in something big!"

For a moment you think it sounds exciting.

She goes on to describe the two groups; one is called a control or standard care, which is just like your regular appointments. The other group is more intense; you have to count your steps, count your calories, weigh yourself every day, and take meal replacement shakes.

You interrupt her and ask about the shakes. You've been so nauseous you're worried about having to drink shakes. She explains that you're given a customized meal plan based on the calories you need to limit weight gain throughout pregnancy. She explains that the US maternal health policy recommends that pregnant women with a high body mass index (BMI) should only gain about half a pound per week.

You think this sounds a bit extreme, but your doctor suggested it might help, so you stay and listen to the woman describe the "assessments": "Both groups have to complete assessments three times during pregnancy, then twice after delivery. The assessments include 7 teaspoons of blood, urine sample, blood pressure, hip, arm, thigh circumference measurements, an oral glucose tolerance test, and weight measurements."

She asks, "Have you ever done an oral glucose tolerance test for gestational diabetes?" You start to explain that in your last pregnancy you had a miscarriage at twenty-four weeks, so you never took a diabetes test.

The woman pauses in recognition, then moves on to review more information about the trial. She explains that someone from the trial will come to your house or to the hospital within seven days of your delivery to collect weight and height measurements. She says something like "unidentified biological samples like blood and urine are stored at repositories." Then she asks how you are feeling.

You feel a lot of different things. But first you tell her that you're a weird case because you had so many complications in your last pregnancy and had so much blood taken throughout. You feel traumatized, but you say that you feel really nervous about blood. You say that you need to check in with your doctor once more before deciding. You go home without signing the consent forms.

A week later, you get a call from the woman from the trial. You're busy with work, so you don't respond. After running it by your doctor one more time, who confirms that it is safe to participate in this type of clinical trial while pregnant, you decide to enroll. Another week passes and she calls again, and you decide to set up the next appointment.

You meet at the same place, and this time you sign all the papers, even the one that says you consent to having genetic tests done on your blood samples and on the cord blood samples collected at birth. But you make one final request: "Please make sure that my personal ID is not going to be associated with this trial, I don't want to be famous."

. . . . .

Why do I place you, the reader, as the "pregnant person" in this narrative? It is to make you feel, understand, and empathize with the process involved in participating in a pregnancy trial. This narrative, and book, are about the tensions between the social, political, and lived experiences of "maternal environments" and the scientific view of such environments. The maternal environment in pregnancy trials is defined as individual pregnant bodies and behaviors. With such definitions in hand, however, is the maternal environment at fault for childhood obesity or toxic chemical

exposure? The key provocation of this book is that while science and society may frame pregnant people as uniquely and totally responsible for the welfare of growing fetuses and children, pregnancy and reproduction are not individual processes. *We all encompass the maternal environment.* We all collectively participate in reproduction, regardless of sex, race, gender, orientation, ability, or fertility.[1] We all contribute to the social, institutional, and environmental circumstances that shape each pregnancy, birth, and child.

How the maternal environment is operationalized in science and society is a political project; framing the maternal environment as only pregnant bodies and behaviors, rather than understanding it as everything that could influence a growing fetus including systems of poverty and racism, engenders social and material consequences for everyone, and particularly for vulnerable populations. Taking our reproductive entanglements seriously and broadening the scope of what counts as the maternal environment is an intervention in individualistic and ineffective approaches to our present and future health.

As the first ethnography of its kind, *Weighing the Future* examines the sociopolitical implications of ongoing pregnancy trials in the United States and the United Kingdom, illuminating how processes of scientific knowledge production are linked to capitalism, surveillance, racism, and environmental reproduction. The maternal environments we imagine to shape our genes, bodies, and future health are tied to race and gender, as well as to structures of inequality. I make the case that science, and how we translate and imagine it, is a reproductive project that requires anthropological and feminist vigilance. Instead of fixating on a future at risk, the book brings attention to how the present—the here and now—is at stake.

The pregnancy trials, also known as prenatal trials, that I study draw from the fields of epigenetics and developmental origins of health and disease (DOHaD) to link pregnant people's behavioral choices, like diet and exercise, with future health risks. Epigenetics, or the study of gene-environment interaction and regulation, is a field of science that examines the inheritance of changes to genetic expression without changes to the DNA sequence itself. Importantly, epigenetics has ushered in a renewed interest in "the environment," which can include the molecular "junk" surrounding DNA, sugar levels in a pregnant body, and carbon

dioxide levels in the atmosphere. DOHaD is a field of study that examines how exposure during critical periods like pregnancy and early development impact health across the life span. Contemporary science frames pregnancy as a critical period of development because it encompasses multiple generations in one: the pregnant body is the first generation, the fetus is the second generation, and the reproductive cells in the fetus represent the third generation.

New research programs across epigenetics and DOHaD are increasingly characterizing postgenomic science. Postgenomics marks a shift away from gene-centered approaches to inheritance and genetic expression.[2] The postgenomic era refers to the time period following the completion of the human genome project at the turn of the twenty-first century.[3] Chapter 1 outlines the fields of postgenomics, epigenetics, and DOHaD by examining their role in pregnancy studies. Epigenetic and DOHaD logics suggest that maternal behaviors and environments in the present can impact both genetic expression *and* future health outcomes. In a postgenomic era, pregnant people are uniquely made responsible for the health risks of future generations.

The scientific and media interpretations of epigenetics and DOHaD theories individualize the health risks of future generations onto pregnant bodies alone. News articles have emerged with titles such as "Pre-pregnancy Diet 'Permanently Influences Baby's DNA'" and "Bad Eating Habits Start in the Womb."[4] These interpretations reflect a key aspect of the burgeoning field: pregnant bodies are at the center of epigenetic knowledge production.[5] Fetuses and reproductive bodies are not only framed as central figures in epigenetics; social scientists even claim that "epigenetics is a reproductive science."[6] Guided by a critical race and feminist lens, I organize such conceptualizations of epigenetics and reproduction into a distinct framework of postgenomic reproduction, explored further later in this chapter.

The introductory vignette draws from hundreds of prenatal trial visits that I observed, listened to recordings of, reviewed through interviews, or conducted myself. My ethnographic and feminist examination of epigenetics, pregnancy trials, and future health shows that despite significant advances in science and technology, the same interventions based on individuals—rather than on structural contexts—are funded, tested,

and used to inform contemporary maternal health policy on obesity and diabetes. A key issue with such individualistic approaches to examining the maternal environment is that pregnant people should not be the only ones held responsible and accountable for present and future health risks. Denying our collective participation in reproduction and continuing to promote individual lifestyle interventions draws resources away from much needed systemic and institutional change. It further risks reproducing knowledge that is not only selectively applying and interpreting new science, but ultimately ineffective in addressing health disparities across race, or what some scholars refer to as racist disparities in health.[7] By examining how contemporary pregnancy trials draw on new science, *Weighing the Future* addresses the question: How is scientific creativity foreclosed by social and political contexts?

PREGNANCY TRIALS IN THE UNITED STATES AND THE UNITED KINGDOM

There are currently more clinical trials that target pregnant people for lifestyle interventions than ever before.[8] Lifestyle interventions focus on changing individual bodies and behaviors and include anything from wearing a pedometer to measure steps; to using a virtual online application for diet and exercise accountability; to a variety of nutritional plans, some of which include replacing meals with shakes. In the past two decades the National Institutes of Health in the United States and United Kingdom have invested hundreds of millions of dollars in pregnancy trials aimed at understanding future health risks associated with obesity during pregnancy.[9] Pregnancy studies have a long history, and only in the past decade or so have maternal health recommendations integrated aspects of epigenetic science and DOHaD to create clinical trials that focus on how food and exercise interventions can impact future health (see chapters 1 and 2).[10]

International lifestyle pregnancy trials are similar in that they target large, ethnically/racially diverse sample sizes; focus on individual behavior changes; and are mainly funded, designed, and implemented in the Global North. I use the term *Global North* in both a critical and practical

sense; it reflects how race and empire are materially and conceptually mapped onto grounded networks, resources, and methodologies of scientific knowledge production, and it captures how most, if not all, evidence-based medicine is funded and designed in North America and Europe.[11] If you were pregnant and recruited into a clinical trial in the United States or the United Kingdom, there would be some key differences, but the process of moving through each phase of the trial would be similar. One reason for this is that prenatal trials are designed in a standard way to facilitate the generalizability of data and results internationally.

The main differences that emerged as significant in my analysis across the United States and United Kingdom were contexts of health-care infrastructures and distinct histories of racialization. Most of the chapters move across the United States and United Kingdom together, but I specifically address the distinct milieus of racialization in these different countries in chapter 3. In 1993, the National Institutes of Health (NIH) in the United States required that all publicly funded clinical trials include "women and minorities."[12] This policy was also taken up in the United Kingdom. As a result, the pregnancy trials that I study in the United States and United Kingdom made a significant effort to recruit ethnically/racially diverse populations, which were distinctly defined and classified in each national context. However, despite the NIH mandate to include more diversity in clinical research, the intended impact of reducing health disparities across racialized groups has not been realized.

Throughout the book I make the case that including diverse groups of people in research and comparing health outcomes across (unstable) categories of race does not ameliorate health disparities because this approach does not effectively examine the role of racism in shaping health outcomes. Diversity and inclusion efforts do not directly address long-term exposure to unequal and unhealthy living conditions. Including more diverse people in clinical research is no doubt a worthy and necessary cause, but I argue that to address issues of equity, evidence-based medicine can and must do better. The conclusion and epilogue provide alternative ways of framing the problems and solutions to future health.

Pregnant people in the United States can access prenatal care through private insurance or Medicaid.[13] Anyone who receives Medicaid in the United States is also automatically enrolled in multiple forms of state

surveillance that are not applicable to privately insured people. The United Kingdom has the National Health Service (NHS), a state-funded system that provides some free health-care options.[14] Prenatal and postpartum care is provided to all UK residents through the NHS. A unique aspect of the NHS is that midwives provide a significant portion of prenatal care. However, who counts as a resident and what health services are available have shifted drastically in the past decade due to anti-immigrant sentiments, Brexit, and massive budget cuts to the NHS.[15]

A snapshot of the maternal and infant health outcomes across the United States and United Kingdom reflects a fairly comparable landscape. The United States and United Kingdom both have higher rates of obesity during pregnancy than other high-income nations. The United States has a higher rate of maternal and infant mortality than other wealthy countries, including the United Kingdom.[16] Black women in the United States have two to three times the rate of premature birth and maternal mortality compared to white women. The US racial disparity in premature birth and death has not changed in the past sixty years, and some trace this disparity back further, to slavery.[17] Similarly, Black women in the United Kingdom have a much higher chance of maternal mortality and pregnancy complications than white British women, regardless of the different health-care systems.[18]

EPISTEMIC ENVIRONMENTS

To situate pregnancy trials and the relevant stakes within broader social and political milieus, I use the concept of *epistemic environments*, inspired by the notion of epistemic infrastructures, which Michelle Murphy defines as the ideas, methods, and economic and political structures that shape how science unfolds.[19] My employment of *environments* instead of *infrastructures* is related to the empirical material at hand: epistemic environments emphasize the ways in which epigenetics and postgenomics have brought a renewed significance to the concept of environments across reproduction. "The environment" and what it includes is precisely what is at stake in the production of scientific, medical, and reproductive knowledge in a postgenomic era.