Juanita Miller lives in a first-floor apartment on a quiet residential street in a predominantly African American community in the San Francisco Bay Area. Her neighborhood, lined with older two-story homes now split into smaller apartment units, is just blocks away from an industrial strip located in the shadows of an elevated highway. I came to visit Ms. Miller on an overcast afternoon in late summer. She took a long time to come to the door. A tall black woman in her fifties, she moved slowly and gingerly, wincing in pain from the arthritis that the recent wet weather had aggravated and breathing laboriously because of her congestive heart failure. The living room in which we sat was crowded with sofas and loveseats, a china cabinet, a huge stuffed animal, and Ms. Miller's wheelchair. She preferred to sit in the wheelchair because it had leg rests that she used to alternately elevate and then lower her legs during my visit. She had
sustained a fall recently and was also recovering from an infection on her leg—a complication of diabetes that had almost required amputation.

My interview with Ms. Miller turned out to be the longest one I conducted. Her medical history of arthritis, diabetes, hypertension, multiple heart attacks, and congestive heart failure was lengthy and complicated. Telling the story of their incidence, development, diagnosis, and treatment inevitably involved extended forays into her personal history. Her subjection to racial and gender discrimination at school, on the job, and at home; her drive to surpass the devaluing expectations of family, teachers, and employers; her experiences of domestic violence and single motherhood; and her lifelong engagement in social and labor activism all became part of the medical story. Ms. Miller did not mince her words as she attributed her bad health to a lifetime of the strains and stresses of this social biography. In her view, “Who has the most checkers, that’s who has the better chance of surviving.” She made it clear that she had not been given many checkers in life and had had to fight for those few that she did have. At the end of our interview, as she walked me to the door, I commented on how informed she seemed to be about her medical conditions, and how much I’d learned from her. She replied, “I’ve been the landlady of this body for over fifty years. I know what makes me sick.”

Mulling over Ms. Miller’s words on my way home, I could not help but be reminded of my encounter with an epidemiologist at a scientific conference some five months earlier. She was exhibiting a poster of her research on the disparities in cardiovascular risk factors between black and white women. According to her findings, black women in her study had more risk factors for heart disease than their white counterparts. When I asked the scientist what she made of this finding, she responded that “socioeconomic status, including occupational category, combined family income, educational level, and insurance status, might have a lot to do with it.” She also hypothesized that diet, sedentary lifestyle, culture, education, and perhaps access to health care may play a role.

The researcher then added that she was involved in another study in which investigators were exploring what prompted people experiencing
cardiovascular symptoms to see a medical provider for evaluation. She noted this to me, she said, because black women, in addition to being disproportionately at risk for heart disease, have also been shown to have high rates of delaying care, which to her had sounded a bit like “blaming the victim.” She suspected that not seeking care had more to do with structural barriers such as lack of time, child care, transportation, access to care, and so on. She related that she had shared these thoughts with the rest of her research team, only to be contradicted by the study’s nursing coordinators—who she noted were black—who told her that “black women could come in but don’t.” They argued that there were also poor white women who had as many barriers yet still sought treatment for symptoms. The principal investigator subsequently speculated to me that maybe “there is a black culture—welfare moms, or whatever—with low education who maybe missed out on the public health messages of the past ten years.” This researcher ultimately attributed the disproportionately high cardiovascular risk of black women to a presumed propensity to delay care and a lack of skill in symptom recognition. These traits, she suggested, were rooted in a pathological culture combined with insufficient education. In advancing these arguments, she bypassed the very kinds of forces that Ms. Miller had so emphatically implicated: the powerful influence of race, gender, and class in stratifying education, economic opportunities, and material conditions, and their subsequent effects on her well-being.

Juxtaposing this epidemiologist’s account with Ms. Miller’s narrative raises a host of questions: Why such divergent views? How do Ms. Miller and this epidemiologist come to such different conclusions about why heart disease befalls one individual or group and not others, and, in particular, the kinds of roles that race, class, and gender play in distributing health and illness? Where do their ideas about disease causes, risks, and determinants come from? What consequences do these ideas have for how we as a society understand health disparities and act to mitigate them? In turn, what particular policies and interventions are seen as rational, legitimate, and effective courses of action? And how are these
processes of rationalization, legitimation, and validation accomplished? This book seeks to answer these questions by critically analyzing ideas about what causes disease alongside ideas about where health inequalities come from.

Explaining Disease, Accounting for Disparities

In order to examine conceptions about what causes disease and health disparities, we need to take a closer look at epidemiology, the science of disease distribution, determinants, and frequency. Its core concerns are with the patterns of health conditions in human populations and with the factors that influence those patterns. Epidemiology thus plays a critical role in shaping our understanding of health and its variation, and in framing public health policies. Epidemiology as a set of social practices both emerges out of and contributes to systems of social classification by race, class, sex, and gender. These classificatory and meaning-making practices are numerous, diffuse, and unremarkable, almost to the point of being invisible. In this way, race, class, and gender become part of our everyday logic or “common sense”—a way of comprehending, explaining, and acting in the world.”

At multiple nodes of epidemiologic knowledge production—grant applications, data collection instruments, statistical software, and journal publications—and in multiple activities such as articulating research questions, collecting and analyzing data, interpreting results, and disseminating findings, epidemiology continually yet often imperceptibly legitimates particular definitions of race, class, and gender and systems for categorizing those differences. Using such classificatory schemes, epidemiology provides readily available explanations for illness outcomes and, in so doing, validates those classifications and categories as objects of biomedical inquiry and scrutiny. These explanations then direct future scientific practices and health-related resources along racialized, classed, and gendered lines. In this fashion, common, mundane, on-the-ground scientific work routinely, yet often invisibly, makes claims about which
social differences matter and how. In short, as the basic science underpinning public health programs, many clinical interventions, and public guidance on avoiding disease, epidemiology engages in the production and adjudication of authoritative claims of how differences matter in heart disease. And it does so in the name of disease prevention and management, the optimization of health and well-being, and the maximization of the value and utility of a populace.

In this book, I focus on the epidemiology of heart disease. On a macro level, cardiovascular diseases—a class of conditions that affect the heart or blood vessels and include hypertension, coronary artery disease, and stroke—have long been the leading cause of mortality in the United States and worldwide. For instance, in 2009, cardiovascular diseases were responsible for one of every three American deaths, and coronary heart disease for one of every six American deaths. Upward of 15.4 million Americans are estimated to suffer from coronary heart disease and almost 78 million from hypertension, or high blood pressure. Projections show that by 2030, an additional 8 million will develop coronary heart disease and 27 million more will have hypertension. These conditions are extraordinarily costly. Coronary heart disease accounted for an estimated $83.6 billion in health care expenditures in 2007 (a 44 percent increase since 1997) and an additional $68 billion in lost productivity. Estimated direct and indirect costs in 2008 for high blood pressure were $50.6 billion. By 2030, projected total costs for coronary heart disease and hypertension are expected to rise to $223.8 billion and $245.2 billion, respectively. It is clear that cardiovascular diseases exact the greatest economic toll of all other health conditions: The combined $143.0 billion spent in 2008 on medical care for heart conditions and hypertension far eclipses the $74.3 billion and $72.2 billion spent on trauma-related disorders and cancer, the next two costliest conditions.

Epidemiologists have been studying the patterns of heart disease for many decades. As a result, there is a vast body of knowledge to consider. For example, black women and men die from coronary heart disease at higher rates than whites, even after adjusting for income level. In 2008,
mortality rates (per 100,000 population) for this condition were 161.7 for white males and 183.7 for black males, 91.9 for white females and 115.6 for black females. Mexican Americans also suffer from higher rates of heart disease mortality than non-Hispanic whites.11

Epidemiologic research has also shown that the prevalence of hypertension is disproportionately high among African Americans, Mexican Americans, and American Indians. In fact, African Americans’ levels of hypertension are among the highest in the world. They are also increasing: The prevalence of high blood pressure among blacks increased from an average of 35.8 percent in 1988–94, to 41.4 percent in 1999–2002. Blacks develop hypertension earlier in life than do whites, and their average blood pressures are also higher. Consequently, sequelae of hypertension also affect blacks far more: Compared with whites, they have a 1.3 times higher rate of nonfatal stroke, 1.8 times higher rate of fatal stroke, 1.5 times greater rate of death from heart disease, and 4.2 times the rate of end-stage kidney disease. One condition that results from both hypertension and coronary heart disease is congestive heart failure; according to one study, the occurrence of heart failure before age 50 is twenty times more common among blacks than whites.12 As expected, then, death rates from hypertension are starkly unequal: In 2008, mortality (per 100,000 population) from high blood pressure was 16.5 for white males, 50.3 for black males, 14.5 for white females, and 38.6 for black females.

This pattern of early onset and higher and earlier mortality among blacks is seen across all cardiovascular diseases. One study found that the disproportionate rates of cardiovascular diseases in blacks compared with those of whites start in young adulthood and increase with advancing age, resulting in 28 percent of all cardiovascular-related deaths among blacks occurring before age 65, versus only 13 percent of such deaths among whites.13

Significant differences by class and by sex also exist in the epidemiology of cardiovascular disease. Among men 25 to 64 years of age, heart disease mortality for those with incomes less than $10,000 was 2.5 times that for those with incomes of $25,000 or more. Moreover, neighborhood
measures of socioeconomic status were also inversely related to fatal coronary heart disease among black and white women and men, but this association was larger for women than for men. Among people with lower educational and income levels, not only is hypertension more prevalent, but also on average, their blood pressure measurements tend to be higher than of those with more education and household income.

Finally, although the epidemiologic wisdom is that women develop heart disease some ten years later than men, the intersecting dynamics of race, social class, and age on women of color and poor women seem to significantly attenuate and even reverse much of this presumed “sex advantage.” For instance, hypertension is more prevalent among men up until about age 55, but thereafter it is more prevalent among women. There are also indications that the influence of class on heart disease is more pronounced for women than for men: The poorest women aged 25 to 64 years were 3.4 times more likely to die from heart disease than those with the highest incomes; this income gradient is much steeper for women than for men.

Altogether, epidemiologic data has built a mountain of evidence that persistent, severe, and consequential inequalities in cardiovascular health exist. These inequalities represent only part of what physicians and health policy scholars W. Michael Byrd and Linda Clayton call “an American health dilemma,” a phrase that echoes Gunnar Myrdal’s historic characterization of the chasm dividing whites and blacks in the mid-twentieth-century United States. But accepting that health disparities exist only further begs the question of what kind of problem they are. Epidemiologic studies have tried to account for inequalities in heart disease by pointing to at least four possible explanations. The first attributes cardiovascular disparities to the uneven distribution of modifiable risk factors, such as hypertension, obesity, lack of physical activity, diet, smoking, and diabetes. And indeed, the prevalence of these risk factors has been shown to differ by race-ethnicity, social class, and gender. Second, unequal treatment of heart disease and its risk factors is seen to result in unequal cardiovascular health status. An impressive number
of studies have in fact documented racial and sex differences in care. Third, possible physiological and genetic differences are hypothesized to account for some health disparities, particularly by race-ethnicity and sex and, indeed, are sometimes considered the key to understanding the causes of complex health conditions like heart disease. Finally, some groundbreaking efforts are currently underway toward more explicitly structural and theoretically informed explanations of how social determinants might be associated with inequalities in heart disease.

But what of those afflicted with heart disease? While the lay people I spoke to as part of my research may have a less formalized and systematic picture of health disparities, the appearance of illness in their own bodies usually initiates a flood of questions: Why me? Why this disease? Why now? Those who must live with diagnosed disease also pay attention to the health of those around them and are often highly cognizant of the unequal toll that cardiovascular and other chronic diseases have taken on their families and communities. They question the distinctive and disproportionate risks to which they and others like them might be exposed. Like epidemiologists, then, lay people’s attempts to make sense of where, when, why, and who heart disease strikes are quests for ways to explain and account for the causes and determinants of the disease and their distribution across populations.

Clearly, the nature of the “problem” of health disparities and of the roles that race, class, and gender play in generating them can be and are understood in multiple ways. These ways of knowing are consequential. The conceptions of human differences they admit, the definitions of the problem they promote, the solutions they promulgate, and, crucially, their status as legitimate modes of knowing in our knowledge-stratified society have deep implications for our negotiations, contestations, and organization of health inequality. It is therefore important to highlight here the recent explosion of research, policymaking, and public attention to the causes of health inequalities. The problematization of health disparities and the mandate for a governmental response are now fairly well institutionalized. In 1993, the National Institutes of Health (NIH)
established an Office of Research on Women’s Health and the National Center on Minority Health and Health Disparities. In 1998, the Clinton administration launched the President’s Initiative to Eliminate Racial and Ethnic Disparities in Health under the auspices of the Department of Health and Human Services Office of Minority Health, which was continued under the George W. Bush administration. In 2010, as part of the Patient Protection and Affordable Care Act, the National Center on Minority Health and Health Disparities transitioned to become the National Institute on Minority Health and Health Disparities (NIMHD). Institute status gives NIMHD a more prominent presence within the NIH structure and authorizes it to plan, coordinate, review, and evaluate all minority health and health disparities research activities conducted and supported by the NIH institutes and centers. Healthy People 2010, a document that outlined health and prevention objectives for the United States for the first decade of the twenty-first century, included eliminating racial and ethnic disparities in health as one of two overarching priorities. In Healthy People 2020, the goals with regard to health disparities have been reframed, to achieving health equity, eliminating disparities, and improving the health of all groups.

But the larger issue of how to think about human differences in health also reverberates throughout multiple other institutional domains. A failed California ballot initiative illustrates how accepted logics about the relevance of human differences for health have entered into the political sphere. In 2003, the American Civil Rights Coalition, headed by Ward Connerly, successfully placed Proposition 54, titled the Racial Privacy Initiative, on the October 2003 California ballot. The Racial Privacy Initiative, which ultimately did not pass, would have amended the state constitution to bar state agencies from collecting, analyzing, sorting, or acting on any data on race, ethnicity, or national origin. Curiously, however, it made a key exemption for medical research subjects, allowing state agencies to continue to classify and analyze them by race, ethnicity, and national origin. Apparently, its sponsors felt that medical research—in contradistinction to other institutional practices—should be assertively race-conscious rather than colorblind.
Contentious debates about the meaning and medical significance of race and the politics of representation in medical research have been ongoing for decades. As the sociologist Steven Epstein has explored, a steady stream of clinical research began to raise the issue of the appropriate place of “race” in health and biomedicine, giving rise to what he calls a new common sense and “biopolitical paradigm of inclusion-and-difference” for medical research. Recent findings over potential differences in the efficacy of pharmacological therapies and in the use of various heart disease–related treatments have raised impassioned arguments over definitions of racism, the nature of race in biomedicine, and the suitability of “racial profiling” in medical research and treatment, spilling over into mainstream media. And in the genomic era, while debates about the relationships among genetics, race, and ancestry remain quite public, many have argued that all the while, scientists have continued to embed genetic understandings of racial differences into their daily practices. Such ongoing and recurring contestations underscore the nagging questions that surround the meanings of race and whether and how it should be used in health research and medical care.

Particular understandings of sex and gender have, like race, imbued medical research. In 2001, the Institute of Medicine (IOM), a part of the National Academy of Sciences, released its report on sex differences in health. Provocatively titled Exploring the Biological Contributions to Human Health: Does Sex Matter?, the IOM Committee on Understanding the Biology of Sex and Gender Differences concluded that sex differences rooted in biology did indeed matter, and it proposed numerous recommendations to remedy what it saw as a deficit of research into the mechanisms and origins of such differences. But aside from brief discussion of the conceptual and linguistic conflation of “sex” and “gender” and the need to clarify their distinctions, no mention was made of gender.

Studies of the consequences of hormone replacement therapy (HRT) constitute one extremely active area of medical research that bears on our understandings of the health effects of sex. In little more than a decade, there has been a complete sea change in medical views on the safety and
efficacy of HRT for disease prevention. Prior to 1998, the epidemiologic and clinical bandwagon was that hormone replacement would not only make postmenopausal women feel better but would also protect them from a panoply of conditions, including heart disease. Since then, however, a flurry of clinical trial results indicates that, at best, these claims have been exaggerated, and, at worst, such advice in fact placed women at increased risk for multiple conditions, including some of those that HRT was thought to prevent. In 2003, for example, The New England Journal of Medicine published final results from two clinical trials of hormone replacement therapy among older postmenopausal women which showed that HRT in fact slightly elevated the risk of heart disease. In the face of such unanticipated findings, it would seem that the stability of the biological construction of sex differences should be threatened. Yet, in 2006, a special issue of the Journal of the American College of Cardiology concluded that the pathological processes and manifestations of heart disease differed systematically for women than for men.

Institutional efforts to shape the research agenda and encourage particular approaches to studying health disparities provide another window into what kinds of explanatory accounts for the health impacts of human differences are valued and legitimated. In 2000, the Office of Behavioral and Social Sciences Research at the NIH convened a conference to critically examine research on the social and cultural dimensions of health. The final conference report featured key recommendations to improve social science research and integrate health research across multiple levels of analysis. In response, two new funding programs were established. The first supported methodology and measurement research—into research design, data collection techniques, measurement, and data analysis techniques—in the social and behavioral sciences. The second funding program supported research on basic social and cultural constructs and processes used in health research, including “the implications of different conceptualizations and measurements of social stratification systems and processes . . . for understanding health at the individual and higher levels of aggregation (e.g., community).” It
was also intended to fund explorations into the social etiology of health and illness “to improve understanding of how macro-level (societal) factors, such as social policies, structures, and cultural norms, are linked to micro-level (individual) factors, such as a person’s behaviors, and ultimately to health.” Yet another funding program, which came as a result of a 2006 NIH-sponsored conference on behavioral and social sciences research contributions to understanding and reducing health disparities, was designed “to encourage behavioral and social science research on the causes [of] and solutions to health and disabilities disparities in the U.S. population.” In 2008 and in 2012, the NIH convened a Summit on the Science of Eliminating Health Disparities, to showcase emerging science that can inform policies and programs to reduce health disparities.

While these last examples could be read as conceptually and institutionally significant moves to rethink and diversify the ways in which we study and understand disease causation and health disparities, there is throughout an overwhelming emphasis on the continued production of expert knowledge. To be sure, multi- and interdisciplinary research, “community consultation,” and community-based participatory research were encouraged, but there was no explicit acknowledgment that lay people too understand the origins of their own conditions in potentially illuminating ways. This is true also of the epidemiologic and medical research described above: Embedded therein is an unspoken assumption that authoritative knowledge about disease causes and health inequalities is the province of credentialed professional experts.

But this need not be the case. Numerous scholars have grappled with the complex issues of knowledge and expert–lay engagement in various ways. Hilary Arksey, for example, found that one lay group organized by those suffering from repetitive strain injury (RSI) collected their own statistics regarding prevalence, developing an expertise with which to challenge the medical establishment. More generally, she argues, lay persons have the potential, through their practical experience and “insider” knowledge, to exert influence in medical fact–building around RSI, though their claims are vulnerable to co-optation by credentialed
medical experts. The sociologist Phil Brown coined the term “popular epidemiology” to describe the collection, analysis, and utilization of data by community activists and families affected by toxic waste. These efforts “repeatedly differ with [those of] scientists and government officials on matters of problem definition, study design, interpretation of findings, and policy applications.” Significantly, popular epidemiology, in contrast to mainstream epidemiology, emphasizes social structural factors as centrally implicated in disease causation. Brown also outlines how lay and professional “ways of knowing” vary in their positions regarding value-neutrality, standards of proof, and uncertain and emerging diseases and conditions. Finally, Steven Epstein uses the term “lay experts” to refer to AIDS activists who acquired the vocabulary and frameworks of biomedicine and parlayed other significant social and cultural resources to become genuine participants in the design and execution of clinical trials. These studies thus examine lay engagements with scientific communities in cases where a small number of “auto-didacts,” in Epstein’s words, within social movements absorb enough of the jargon and concepts of the relevant science to forge and force connections with the credentialed establishment and to position themselves as credible interlocutors. That is, the grounds upon which lay people can be understood to possess “expertise,” in the extant literature, are based upon their scientization—their acquisition and mobilization of the concepts, frameworks, and vocabularies of scientists themselves.

But for these notable exceptions, however, a conjoint consideration of lay and expert knowledge has been understudied. This is the case despite a widespread call in science and technology studies to analyze expert–lay relations. This book seeks to answer this call, to take seriously the notion that knowledge production—whether through scientific methods or lay experience—is suffused with social and political concerns. Thus, to explore the multiple ways in which we think about and understand the causes and origins of health inequalities, I interviewed both epidemiologists who research heart disease and people of color who live with it. I also conducted ethnographic observation and informal interviews
at epidemiologic conferences where results of studies were shared and discussed. And I analyzed papers, commentaries, and editorials published in major epidemiology journals. In this book, I outline the major dimensions of a deep divide that I found between epidemiologists’ and lay people’s ideas about human differences and their consequences for heart disease. The conceptual chasm revealed by the two vignettes in this Introduction’s opening is, I argue, representative of fundamental disagreements about the nature of social difference, their significance for health and disease, and the validity and credibility of different forms of knowledge.

The Science–Lay Divide: Individualized Differences versus Embodied Inequalities

As the chapters that follow demonstrate, I found that epidemiologists ritualistically included various measures of difference in their research to limit or describe study samples and to stratify, adjust, and interpret results. In so doing, investigators infused such human features as race, ethnicity, social class, sex, and gender with particular meanings and definitions. With respect to race, they interpreted the meanings of racial differences through a cultural prism. Like the epidemiologist I encountered at the outset of this Introduction, they tended to attribute racial disparities to “cultural” or “ethnic” differences, related to the customary values and practices of a racially or ethnically defined social group. Whites remained essentially acultural. When it came to social class, epidemiologists often agreed with the lay people in my study that its health effects are produced by differential access to resources and opportunities, social environments, living conditions, and the stress of chronic deprivation. Yet, at the same time, epidemiologic conventions for measuring economic status predominantly involved individual-level variables that only hinted at the complex social processes that govern and produce class stratification. Finally, regarding sex and gender, epidemiologists viewed sex as a crucial axis of analysis because of its definition as a biologically
meaningful distinction, while gender—as a reference to the social distinctions and relations among groups based on sex—was almost completely ignored. I found epidemiologists to be overwhelmingly concerned with “the estrogen connection”—with explicating the potential (and often presumed) links between women’s exposure to endogenous estrogen and their lower incidence of heart disease.

In contrast to epidemiologists, the African Americans, Asian Americans, and Latinos with heart disease whom I interviewed articulated complex and nuanced understandings of the intersecting relationships between group status, relations of power, and well-being. They considered the health effects of racial, class, and gender differences as mediated through profoundly and intrinsically social processes. In their view, race, class, and gender operate together to structure their everyday experiences and life chances that, in turn, affect their risks for disease. While the meanings they assigned to human differences were highly variable, lay people talked about the risks posed by race, class, and gender in terms of the consequences inequality had on their sense of self, everyday interactions, and the economic and environmental conditions of their lives. For them, the health effects of racial difference stemmed from the material and interlocking consequences of racial inequality. Their racialization as members of specific racial groups structured and ordered their everyday experiences and conditions of life that had, in their view, direct implications for their cardiovascular risk. Lay people, like epidemiologists, saw both sex (as a biological attribute) and gender (as a system of social arrangements, processes, and practices) as binary in nature. However, they starkly disagreed with scientists in their belief that the cardiovascular risks differentiating women from men were based in gendered inequality rather than in sex differences. And with respect to class, lay people parted ways conceptually from epidemiologists by continually returning to the refrain that social class was intimately intertwined with the dynamics of race.

This underscores a broader divide I found between lay people and scientists on the issue of intersecting dimensions of inequality. In short,
many lay participants saw social experiences, institutions, and structural arrangements organized along intersecting racial, class, and gender lines. They spoke, for example, of how access to educational opportunities was highly constrained by their race, class, and gender and how this then shaped their economic trajectories throughout life. They described racial and gender segregation in the labor market and the gendered division of reproductive labor. The multiple means through which differences were made meaningful, and their interactional and institutional consequences for the social worlds of people of color, in turn exacted costs to their health. These lay perspectives were rooted in views of society as hierarchical and of positions within that hierarchy as relational—that one’s conditions of life and well-being are indelibly shaped by the histories of social relations between one’s own and other groups.

Along all three dimensions of human difference, then, what lay people perceived to be the systematic stratification of everyday experiences and conditions of life became transposed in epidemiology into a set of individualized, discrete, sociodemographic variables of racial categories, socioeconomic status, and sex. That is, epidemiology devolves complex, intersecting, and relational inequalities of race, class, and gender into individual-level and highly reductionist measures of standardized racial categories, socioeconomic status (as measured by income, occupation, and/or education), and sex, respectively. (In this book, therefore, I use the terms “race,” “class,” and “gender” when referring to those social relations of power, and “racial categories,” “socioeconomic status,” and “sex” to refer to the individualized, reductive measures of epidemiology.) Through such individualizing and devolutionary practices, I argue, epidemiologic knowledge furthers biomedicalization—the expansion of the jurisdiction of medicine through means that are often simultaneously scientific, technological, economic, and organizational. More specifically, epidemiology participates in stratified biomedicalization, which emphasizes the selective and strategic nature of biomedicalization, its unequal (and sometimes unintended) effects across populations, and how these may exacerbate rather than ameliorate social inequalities along
many different dimensions. Here, cardiovascular epidemiology is an example of stratified biomedicalization because it categorizes, selectively monitors, and attempts to regulate and intervene on bodies and groups defined as “different” in disproportionate ways. This epidemiologic way of knowing turns these bodies and groups into scientific objects of scrutiny, triggers the use of clinical and other medical practices on them, and places them within specific social and organizational arrangements such as public health and health promotion programs targeting “at-risk” populations. These disparate disciplinary and normalizing practices in turn reinforce biomedical and commonsense logics about differences and disease. As a result, the conceptual divide that exists between scientific and lay understandings of race, class, gender, and cardiovascular risk has enormous consequences for clinical practice, public health, and health policies, as well as societal ideas about race, class, and gender.

The Social Production of Scientific Credibility

As readers have probably already surmised, however, the science–lay divide and epidemiologic biomedicalization are not simple stories of scientific myopia circumventing “real,” authentic experience, or of scientific “discovery” and authoritative expertise invalidating anecdotal, “subjective” perception. First, there was significant heterogeneity and complexity within the epidemiologic and lay accounts of heart disease risk and causation that I gathered during the course of my research. Individuals from both participant groups often expressed outwardly contradictory views within the same interview, holding simultaneous beliefs about the health effects of human differences that seemed paradoxical. But what may appear to be conceptual confusion is actually a reflection of the mutable, multivalent, and intensely personal and political nature of race, class, and gender. In this book, I try to highlight this complexity and heterogeneity.

Second, the fault lines run not only between what epidemiologists versus lay people believe, as might be expected, but also between what epidemiologists think from what they actually do as scientists. In fact,
there was at times a somewhat surprising amount of agreement between researchers’ reflections on the meanings and implications of human difference and those of people of color with heart disease. For example, I found that both groups of participants repeatedly raised concerns about the problematic measurement of race, its ambiguous meaning in a world of multiraciality and shifting racial categories, and the debatable utility and significance of findings of racial differences for clinical and public health. The epidemiologists and lay people I spoke to also shared relatively similar views on the significance of social class for health: that class shapes life experiences and conditions that in turn stratify people’s abilities to care for themselves and to control their exposures to disease risks. On the other hand, while both epidemiologists and lay people agreed on the “naturally” dichotomous nature of sex and gender (that there are two and only two mutually exclusive categories), their understandings of the pathways through which those categories shaped health were vastly different. Yet my analysis shows that, despite such variations in how race, class, sex, and gender were conceptualized, social differences were incorporated into epidemiologic practice in a highly ritualized manner, uniformly and routinely included as individual-level, standardized, sociodemographic variables in research.

In fact, the custom of including racial categories, socioeconomic status, and sex in epidemiologic studies was so taken for granted that in presentations and conversations about their methods, researchers often referred simply to “controlling for the usual suspects” as a shorthand gloss for the practice. This “usual suspects” approach encompasses both a kind of conceptual devolution—wherein complex, manifold social processes are flattened into individual-level characteristics—and methodological routinization as a standard operating procedure. That is, the “usual suspects” approach has become a black box, to use a metaphor originally from cybernetics that refers to the practice of visually representing complex processes as a box with only the inputs and the outputs specified, without the need to detail the contents of the box itself. The science studies scholar Bruno Latour argues that black boxes are
created when many elements and processes are made to fit together into a machine or assembly that in fact acts as one.47 The black box metaphor is often used in situations wherein scientific claims and procedures are perceived as facts and routines, despite their often having a whole history of debates and controversy.48 Thus factness, ritualization, and taken-for-grantedness are actually achieved, rather than being presumed to reflect the natural order of things. Yet in the case of my research, a number of epidemiologists object to the practice of the “usual suspects” on fairly fundamental grounds, despite its pervasive and even obligatory nature in their discipline.

Why, then, has the inclusion of these individualized measures of difference become so black-boxed, even when the contents of the black box, so to speak, are under dispute? I argue that it is because the “usual suspects” approach has become integral to the construction of scientific credibility and the management of uncertainty. The value of epidemiology as a scientific discipline is seen, both inside epidemiology and beyond, to depend upon its ability to achieve and maintain credibility. More specifically, the social and scientific trustworthiness of epidemiology rests upon scientists’ successfully complying and coping with a number of political, methodological, and economic requirements and constraints. These include imperatives for exhaustive measurement, regulatory mandates for diverse study samples, and the need to deal with inadequate theoretical models and data. Any failure to meet these requirements seriously undercuts epidemiologists’ ability to make and defend their scientific claims. In fact, epidemiologists face scrutiny and judgment on a number of fronts. First, as part of a professional scientific community, epidemiologists are acutely cognizant of how their fellow scientists regard their work. Also, epidemiologists have come to occupy a very public role as expert authorities on disease risks and determinants. And finally, they have to be accountable to their funders in order to continue to receive the resources necessary to do research. The epidemiologists in this study managed the varying uncertainties that threatened to undermine the integrity of their research by fulfilling specific methodological, political,
and economic contingencies important to these constituencies, thereby maintaining the kinds of scientific and social credibility called for on each of these fronts.

Thus I found that the “usual suspects” approach offered epidemiologists the best available, “good enough” tool to deal with the most common sources of uncertainty. The “usual suspects” approach persists as a standard operating procedure in epidemiology because it promotes the production of credible epidemiologic claims. But in so doing, this ritualized inclusion of individual-level, demographic variables has important consequences for research on the etiology of heart disease. First, it institutionalizes the understanding of what I and the lay participants argue are social differences as individualistic ones. Second, these individualized variables all too often serve as a first and final explanation for group differences seen in health status and disease outcomes. That is, they provide a readily available account for why such differences exist, in ways that deflect the focus of epidemiologic investigation away from race, class, and gender as causal forces in and of themselves. And finally, the “usual suspects” approach encourages an atomistic and piecemeal treatment of race, class, and gender—as independent and discrete explanations for disease variations, rather than as interdependent, synergistic, and intersecting dimension of inequality. Because of the need to produce and sustain credibility, the heterogeneity, complexity, and even uncertainty that exists both between and among epidemiologists and lay people are black-boxed, and social relations of power are made orderly and socially and scientifically intelligible through their transposition into standardized variables of race, socioeconomic status, and sex. In the process, this black box comes to be seen as robust even when its content is not; epidemiology endorses and promotes its use, even as individual epidemiologists take issue with it. Thus, the story of the science–lay divide that this book tells includes an account of how the practices and infrastructures of epidemiologic work and, importantly, standard definitions of what counts as legitimate and “doable” research are co-produced along with epidemiologic conventions regarding individualized measures of social
difference and biomedicalizing ideas about the health effects of those differences. In truth, the gulf between scientific, expert ways of knowing heart disease and lay perspectives on its causes is as much a hierarchy and an uneven playing field as it is a divide.

A Look Ahead

The research on which this book is based was conducted using several methodologies. I conducted participant observation at conferences where epidemiologic studies are presented, such as the American Heart Association Scientific Sessions, the American College of Cardiology Annual Meetings, and the American Heart Association Cardiovascular Disease Epidemiology and Prevention Conferences. I also collected data via participant observation at various health education events, such as lectures and symposia on heart disease open to the public. I conducted in-depth interviews with a purposive sample of epidemiologists who had published and/or were involved in studies investigating racial, socio-economic, and gender differences in heart disease. I also interviewed a convenience sample of people of color (African Americans, Latinos, and Asian Americans) residing in the larger San Francisco Bay Area who had been diagnosed with heart disease. I asked all the participants to give themselves pseudonyms. In addition, I changed the names of all other people, places, and institutions mentioned in the interviews to protect the identity of the participants. I use “Dr.” to indicate epidemiologists, and I use “Mr.” and “Ms.” to indicate lay participants. And finally, I analyzed literature published since 1985 on the practice of epidemiology. A more extensive description of research methods can be found in the appendix.

My investigation was both guided by and reflects on several theoretical commitments that, while distinct, are interrelated in ways that I wanted to explore further. Throughout my analysis I rely on concepts of biopower and biopolitics and examine how redefined ideas of the state, sovereignty, power, and subjecthood coalesce in debates about health
disparities and their sources. I also wanted to empirically examine theories of intersectionality to better grasp how interlocking systems of oppression shape both the distribution of life chances and the risk of risks, as well as the production of authoritative knowledge about disease causation and health inequality. Finally, I was deeply influenced by the concept of social conditions as fundamental causes of disease and wanted to extend, through my empirical investigation, our current understanding of what those fundamental causes are and how they operate. These three sets of commitments constitute the conceptual foundations for this book, and I provide an overview of each of them in chapter 1.

To set the stage for the remainder of this book, chapter 2, “Disciplining Difference: A Selective Contemporary History of Cardiovascular Epidemiology,” offers a history of cardiovascular epidemiology in our contemporary era. Drawing on secondary sources as well as on interviews and observational data, I trace the emergence of the current ruling paradigm of disease causation—the multifactorial model—and examine its theoretical tenets and implications for the study of social disparities in cardiovascular disease. I then describe several key events in the development of cardiovascular epidemiology. Over the course of this history, epidemiology as a discipline has increasingly articulated its public role as the official producer of scientific knowledge on disease determinants, and the rational arbiter of prevention advice. In so doing, I argue, epidemiologic knowledge has come to have a kind of everyday salience as a form of expertise with which people now regularly engage, interact, and negotiate. Moreover, epidemiology has always influenced and been shaped by social ideas about human difference, from its historical concerns with particular subpopulations (people of color, immigrants, the poor, and women) to the contemporary study of health disparities. I then turn to an analysis of several conceptual and methodological dilemmas in epidemiology that are especially acute in the study of racial, class, and sex/gender differences, such as the problem of establishing causality and the resulting reliance on observational studies. The chapter closes with a critical review of the typical approaches in epidemiologic research on heart disease disparities.
In chapters 3 through 5, I explore the ways in which epidemiologists and people of color with heart disease understand the roles of race, gender, and class differences in heart disease. I analyze the varied meanings of race, class, and gender and how they are mobilized, deployed, and interpreted in epidemiologic and lay accounts of cardiovascular risk and incidence. The meanings of such social differences are neither intrinsic nor self-evident. Rather, as epidemiologists and lay people invoke notions of race, ethnicity, class, socioeconomic status, sex, gender, and so on in claims about disease causation, they continually redefine and negotiate the meanings they attribute to these social features, and the differences they make in heart disease.

Examining the meanings of “difference” shows us how “difference” is made meaningful; that is, exploring how race, class, and gender are defined tells us something about how they function and are made to do work within systems and relations of power. Such differences are therefore “real” in the sense that they are consequential—such social constructions form the basis for intersecting processes that exert concrete and material though changing and complicated effects on people’s sense of self and of group identity, their life chances, and their experiences. Because of the authority accorded to epidemiology as a scientific discipline, it authorizes ideas about what kinds of differences matter, how they matter, and how they should be defined. Thus, epidemiologic conceptualizations of race and its health effects have a powerful capacity to shape what we believe to be true about individuals and groups of different races, and whether and how we act upon these beliefs.

As such, chapters 3 through 5 argue that epidemiology functions as a biopolitical project, a key contemporary site of biopower, and an active participant in the construction of biomedical differences and their social organization in interlocking relations of power.51 Epidemiologic research taking place every day authorizes particular schemes for categorizing human beings and the surveillance activities, health policies, and clinical practices built upon such classifications. Scientific categories and constructions of difference help to organize governmental efforts to
administer and regulate the health and vitality of individuals and populations. Moreover, as the boundaries between the worlds “inside” and “outside” science become increasingly porous, and the culture of biomedical science increasingly contributes to popular culture, conceptions of bodily “differences” like those constructed in cardiovascular epidemiology critically inform those mobilized in everyday life. Thus these chapters explore the question of how differences are made to matter in epidemiology—how epidemiologic methods of sorting people become part and parcel of efforts to stratify them, and how, in turn, stratification processes depend upon sorting mechanisms.

But at the same time, alongside epidemiologic classifications exist people’s own understandings of the ways their race, class, and gender do or do not influence their health. The ways in which they make sense of heart disease constitute complex processes that draw upon many sources, including but not limited to scientific ones. I consider how lay participants in my research view the usefulness or relevance of epidemiologic knowledge about “risky differences” and how their social contexts and experiences shape their integration and negotiation of that knowledge in their everyday lives.52 Furthermore, the experiences and knowledges of individuals with heart disease provide alternative, intersectional understandings of how myriad processes through which their race, class, and gender are embodied come to have consequences for their health. The experiential knowledge of people of color who live with heart disease—as individuals implicated by intersecting axes of power like race, class, and gender—thus serves as a critical contribution as well as potential counterpoint to “expert” epidemiologic knowledge.

As we shall see, considerations of race, class, and gender cannot be neatly divided into three separate, successive chapters. Instead, both epidemiologists and lay people of color living with heart disease invoke combinations of these dimensions of difference in ways that indicate the conceptual complexity of their interactions and intersections. So throughout chapters 3 through 5, I describe how these differences are invoked in multiple, intertwining, and conjoint ways and analyze what
such invocations indicate about how various groups see the nature of difference, inequality, and their influences on health.

Chapter 3, “The Contested Meanings and Intersections of Race,” takes up the often fraught issue of race, which, in epidemiology, is most often measured by self-classification into one of the racial and ethnic categories standardized by the U.S. Office of Management and Budget. I found that epidemiologists readily expressed profound uncertainties about the meanings of race, its appropriate measures and interpretations, and its implications for disease prevention and public health policy. Yet my analysis also shows that it is ritualistically included in their research. In so doing, epidemiologists implicitly infused “race” with multiple meanings and definitions. Most predominantly, they interpreted the meanings of racial differences through a cultural prism. In contrast, people of color with heart disease tended to articulate how social inequalities along racial, class, and gender lines structured their everyday experiences and life chances that, in turn, affected their health. Race was experienced as a master status, shaping social encounters and educational and economic opportunities in ways that exacted a toll on their psychic, mental, and bodily health. But race was also experienced as intersectional as well, inextricably intertwined with experiences of class and gender; thus chapter 3 tries to capture these experiences of intersectional inequality.

Chapter 4, “An Apparent Consensus on Class,” turns to considering the issue of class. In contrast to the very divergent scientific and lay perspectives on race, I found a good deal of consensus on the significance of class differences for health. Both epidemiologists and people with heart disease unequivocally pointed to structural dynamics of class inequality—its effects on differential access to resources and exposures to myriad health risks—in their causal accounts of heart disease. The appropriate conceptualization of class was seen by both groups as indisputably about differences that are social in nature. At the same time, however, epidemiologists were inclined to invoke individualistic explanations for socioeconomic differences that indict health behaviors and the cultural milieus within which they are presumed to arise. They also invariably
expressed concern over confounding between class and race and how best to separate their effects through statistical techniques. Lay people of color, on the other hand, tended to emphasize racial and class stratification as intersecting and mutually dependent processes.

In chapter 5, “The Dichotomy of Gender,” I position gender as an interesting counterpoint to race and class. Importantly, neither epidemiologists nor lay people questioned that gender and sex are binary in nature, and self-evidently so. Within epidemiologic circles, the notion of gender differences in heart disease as rooted in biology was completely uncontroversial. The biological distinctiveness of heart disease in women versus men was considered the natural order of things. In contrast, though, I found that lay people very rarely invoked biological differences of sex. Instead, working-class women of color in particular referred to interlocking dynamics of race, class, and gender that stratified their educational opportunities and structure a racially and sex-segregated labor market. Those employment opportunities available to them were largely restricted to low-paying jobs, with little potential for advancement, minimal job stability, and little power over their hours, pace of work, or the nature of the work process. Such occupational stratification, along with a disproportionate share of childrearing responsibilities (what feminist scholars have termed “reproductive labor”), represents, in these women’s eyes, critical sources of cardiovascular risk that entwine gender with race and class in interlocking systems of inequality. Therefore, it is in also in this second sense that gender can be seen as dichotomous, invoking oppositional understandings of its nature—as biological versus social—and consequences for health that cleave along a science–lay divide.

In chapter 6, “Individualizing ‘Difference’ and the Production of Scientific Credibility,” I move from the issue of how epidemiologists conceptualize the meanings of human differences for heart disease to consider how they manage those differences in their everyday scientific practices, and why. Using interview and observational data, I explore the ritualized conceptual and methodological devolution of racial, class, and gender differences—the “usual suspects” approach—and analyze how it is
integral to the construction of scientific credibility, even as a growing number of epidemiologists question this practice at a fairly fundamental level.

Finally, in the Conclusion, I summarize the key arguments and frame the implications of my findings for health policy and for future research and scholarship in health disparities, expert–lay relations, inequality, and power. Because epidemiology is the science of choice for public health policy and decision making, we must understand and take into account the conditions under which that kind of knowledge is being produced. Conventions and techniques which satisfy a number of methodological, political, and economic contingencies that must be met in order to achieve and maintain scientific credibility constrain epidemiology’s ability to elucidate how relations of power act as fundamental causes of disease, placing people defined as different “at risk of risks.” That being said, however, there is burgeoning interest in and effort devoted to understanding the social determinants of health, the so-called unnatural causes of disease, as one television series puts it. Indeed, the divisions explored in the chapters to come run not just between epidemiologists and lay people as between what epidemiologists think and what they actually do as scientists. Many of them would in fact agree with lay people’s accounts of heart disease, which support the notion that conditions of social inequality function as fundamental causes of disease, by stratifying life chances, resources, and the conditions within which health can be promoted, maintained, and/or undermined. Yet the credibility-generating effects of epidemiologic conceptions of difference—as individual-level risk factors—cannot be ignored. Consequently, I conclude that more comprehensive answers to the question of how difference matters require different ways of obtaining those answers and different ways of producing knowledge, and thus alternative definitions of credibility and expertise.