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Healing Social IIIs through Sexual Health Research in Mexico

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EMILY A. WENTZELL

# COLLEC-TIVE BIOLO-GIES

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Duke University Press Durham and London 2021



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EMILY A. WENTZELL

DUKE

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For Adam, Elliot, and Simon, who helped me understand all that "living for others" stuff in chapter 4



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# PREFACE: COLLECTIVE BIOLOGIES IN THE COVID-19 PANDEMIC AND BEYOND

The pandemic has been a hell of a way to demonstrate this book's relevance.

This is a book about how people in a Mexican city destabilized by prepandemic economic and narcoviolence crises used a seemingly individual act—participating in medical research—to help others. They hoped to help by supporting science in the abstract, disinterested way imagined by Western medical ethics boards. Yet they also hoped men would directly benefit from the medical testing they received and that those benefits, in turn, would concretely enhance the embodied well-being of specific groups of others. The medical research participants I worked with understood themselves to be members of groups at different scales, from their families to the Mexican populace, whose collective, embodied futures were determined by all members' actions.

Here I call these bodies "collective biologies." My goal in doing that is to offer a way to theorize the nonindividual and embodied consequences of understanding oneself as part of a physically and socially interrelated group. It is obvious, though important, to note that everyone and everything is interrelated in a general sense. In this book I offer a way to theorize a particular kind of interrelationship. I analyze the ways that people's experiences of belonging in culturally recognizable groups, such as couples and congregations, shape their daily life actions and, in turn, influence collective well-being. I investigate how people's beliefs about the boundaries and contours of their own relationships with specific sets of others have embodied consequences for those others.

For the research participants I worked with, their memberships in these biosocial collectives were unremarkable, often implicit truths fundamental to daily life action. Theorizing them explicitly is my way of mapping the collective consequences of one ethnographic example of medical research. Further, it is an effort to provide a model for identifying how cultural

ideologies of interrelatedness become embodied on greater-than-individual levels in other cases.

It is no accident that I felt called to try to understand this phenomenon while experiencing new forms of collective biology in my own life. In what could be considered intensive participant observation in embodied relatedness, I gave birth to two children between doing the fieldwork for this book and completing the final manuscript. These new beings depend on me and my husband to meet their needs and to engage in the joyful and exhausting social interactions that make us all people in cultures. I knew that kids need care. I naïvely did not realize how extensive the embodied consequences of providing it would be, from the surgical scar on my wrist that reflects the repetitive strain of childcare to the vastly different calculation of the consequences of my own risk taking that now shapes every new move I make. As members of a nuclear family in a society in which that unit is framed as the main locus of care, what happens in one of our bodies influences quite concretely what happens in the other three's bodies.

This became painfully clear when the COVID-19 pandemic struck. Our nuclear family became a bubble, and our interdependence and shared vulnerabilities, and the varying porosities of our collective bodily and social boundaries, became the main driver of every action we took. I had written about Mexican medical research participants trying to care for collectives amid crisis. Now I was consciously experiencing the state of "living for others" that people had told me about in our interviews not only through new parenthood, but also through my hopes that my own actions would protect the collectives to which I belonged from the harms of the COVID-19 pandemic. Like the research participants I interviewed in Mexico I hoped to be able to use my individual actions to effect change in several collectives, at multiple scales. For example, I hoped changes like teaching online would not only protect my family, but also contribute to the well-being of larger collectives such as my university community.

Yet being American during the pandemic, I have also experienced a cultural form that is opposite to my own hopes and those voiced by Mexican research participants: the refusal of collectivity. I live in Iowa, a midwestern U.S. state whose government refused to mandate masks even when we topped the global charts for COVID-19 positivity rates. Rejecting collectivities does not actually make the individualist fantasies fundamental to Anglo-American culture true or seal our bodies off from one another. We are all still interrelated, and your refusal to wear a mask can still sicken me and my

children and their day care teachers and their families. But that refusal does preclude the kinds of care we can achieve when we understand ourselves to be members of specific groups affected by other group members' actions and bodies, and live accordingly.

While I feel them keenly as a new parent in a pandemic, this book's insights into enacting or refusing collective biologies extend past any moment or place. For instance, COVID-19 will eventually recede. Yet the ongoing pandemic of racism, disproportionately directing viral and other dangers to people of color, harms on a longer timeline. Many activists' efforts to redress this draw on ideologies of collective biology. Conversely, people's efforts to maintain and profit from institutionalized inequality might involve rejection of collectivity. Mask refusal as performance of Anglo-American individuality could fall into this category. Yet as American white supremacists' actions terrifyingly show, explicit efforts to maintain racialized inequalities can also represent perverse efforts to care for collective biologies to which people believe they belong. In the context I discuss in this book, people's understandings of themselves as Mexicans simultaneously make it feel possible for them to use individual medical research participation to aid the national populace, and reify the racial categories that naturalize gender inequality via machismo, and marginalization of Indigenous people and other Mexicans excluded from national narratives of progress through mestizaje.

I offer these examples of racialized collective biologies here both to highlight the relevance of the analytic of collective biologies in and beyond our current moment and to stress that this approach can be used to understand harms perpetrated in the name of promoting a collective's well-being. Collective biologies themselves are not inherently positive. Yet I hope that the analytic of collective biologies that this book presents can do some modest good.

In disciplines from anthropology to biology, we are developing new ways to understand the fundamental interrelatedness of the social and material aspects of the world, without reifying the ideas of a bedrock, essential "nature" that have created and justified so many forms of inequality. I hope that the concept of collective biologies will contribute to that work. I hope it will help us identify how the ideologies of collectivity present in particular places and times influence the embodied well-being of the people imagined to belong to those collectives. I hope it can be applied in a way that enables greater-than-individual bodies to be studied and understood in fields such as clinical research, which currently focuses on individuals even



when investigating population-level phenomena. Finally, in a desire intensified by the desperation of the unmitigated pandemic and the exhaustion wrought by caring for those two new humans amid it, I hope that readers will be inspired by this book's examples of naming and caring for collectives to think in fresh ways through the collective consequences of their own actions, and to care for one another.

—October 15, 2020



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# SEXUAL HEALTH RESEARCH, RELATIONSHIPS, AND SOCIAL CHANGE IN CUERNAVACA

Carjacking, Conversion, and HPV Research Participation

Arturo's path to becoming a medical research participant began when he was locked in a car trunk, praying for his life. The forty-five-year-old taxicab driver lived in the central Mexican city of Cuernavaca, a once-peaceful area stricken by an unprecedented wave of narcoviolence. One night, he was carjacked. Two men beat him and locked him in his trunk. They used his cab to transport drugs through the night. As he lay in the dark, Arturo made a promise to God in exchange for survival. Thinking of his relatives who had converted to evangelical Protestantism and "always carried their Bibles with them," he told God that he would convert. He also swore to "be a better husband and father" if he lived. At dawn, the carjackers opened the trunk, and one prepared to shoot Arturo in the head. He pulled the trigger, but the gun jammed. The men got scared and ran off, leaving him alive. Arturo believed this was divine intervention.

Five years later, I sat with Arturo and his wife, Ade, around a desk in a medical examination cubicle. We were in the Cuernavaca office of the Human Papillomavirus in Men (HIM) study, a multinational observational

research project funded by the National Institutes of Health that tracks the occurrence of that sexually transmitted virus in male research subjects over time. Ade was trim, with short, stylish gray hair and a French manicure. Arturo was also graying, but stockier, dressed smartly in a polo shirt and crisp khakis. The talkative couple were quick to laugh and complement each other and eager to discuss the intimate and sometimes painful experiences they had lived through. Arturo's brush with death was one of the worst; Ade recalled waiting as he failed to come home, hopefully imagining nonlethal reasons such as car trouble but fearing the worst amid the rash of violent crime. Yet they also said the experience led to positive changes for Arturo as a man and for them both as a couple. Arturo kept his promises to God, converting and striving to keep up with the emerging local ideal of emotionally open masculinity by being a more dedicated, caring and present spouse and parent.

His enrollment in the HIM study was a part of that transformation. Ade had heard about the HIM study in her work as a nurse at the Instituto Mexicano del Seguro Social (IMSS), the federal health agency that administered the study in Mexico. She suggested that he join, since it seemed in keeping with his new emphasis on caring for his family and helping others. They believed that Arturo's getting tested for the often-asymptomatic human papillomavirus (HPV) would protect both his and Ade's health, as well as that of other people. Ade said, "You're supporting an investigation, right? That can help to prevent [bad] experiences for people down the line." Arturo added that the international study could have "a benefit for the whole world." It could also model a way to be manly by helping others in ways that countered his attackers' violent and careless masculinity. The couple saw Arturo's participation in medical research as a way to care for themselves, help others, and help him to be the new kind of man he wanted to be.

In this book I follow middle-class, heterosexual couples such as Ade and Arturo through four years of men's participation in the Cuernavaca him study. Longitudinal, observational medical research such as the him study does not test clinical interventions. Instead, it uses repeated clinical testing to assess change over time in participants' bodies. This kind of medical research takes up only a small part of a participant's daily life. Yet it can be consequential. For example, when a man unexpectedly tests positive for an asymptomatic hpv infection, it can cause marital problems and lead to fear about his partners' vulnerability to hpv-related cervical cancer. However, as for Arturo, research participation can also help a man live out his goal of helping others and enable him to care for his and his spouse's sexual health.



Medical research designers and regulators generally understand participation as an individual experience with largely biological consequences. Participants' bodies are the primary objects of medical study. Participants' contexts—such as Arturo's close-knit marriage and traumatic encounter with rising narcoviolence—are seen as biologically relevant only in terms of how they influence participants' health and adherence to study protocols. Yet a rich body of social-science work shows that context matters deeply for participants' research experiences, which can be profoundly social, as well as physical. This work also critiques the idea that participants are passive "human subjects" of research. Research that focuses especially on impoverished and marginalized people's immersion in the globalized world of clinical trials has demonstrated how people often actively seek inclusion in studies and use research experiences to pursue broader life goals.

Those insights inspired my research into the ways that middle-class, unpaid participants might incorporate longitudinal observational research into their broader life projects. What it means economically and structurally to be "middle class" varies widely. Yet the term identifies a shared subject position from which people who understand themselves as precariously economically mobile and capable of creating change have driven the spread of self-consciously modern ideals and practices, adopting and promoting new forms of marriage, worship, and health behavior (cf. Freeman 2014). While HIM participants and their partners had varying levels of economic stability, they shared an understanding of themselves as secure enough to work toward societal change yet poor enough to be free of the corrupt selfabsorption they attributed to Mexico's elite. Here, I investigate how people sought to meet both class-based economic needs and social goals in part through participation in medical research.

I analyze how people's cultural ideologies regarding health—including gender, race, and the fundamental nature of personhood—not only influenced their own experiences of medical research, but actually enabled them to incorporate research participation into wide-ranging social and biological goals at the levels of the couple, the family, and the Mexican populace. Amid violent instability and government inaction, middle-class HIM study participants sought venues for doing good that came to include medical research enrollment. I found that couples hoped to change their own and others' lives for the better through men's unpaid participation in HPV research. This hope depended on a fundamental rejection of the idea that medical research was an individual pursuit. I contend that this rejection reflected a local cultural ideology of personhood that cast Mexicans as members of a racially interrelated social and biological whole rather than as members of a society composed of a collection of individuals. They saw themselves as components of what I call a "collective biology"—an interconnected biosocial group whose behavior and biology could be altered via the actions of constituent parts of the larger whole.

I argue that HIM participants' and their partners' understandings of their bodies and society as collective rather than individual fundamentally influenced their study experiences. This ideology enabled them to incorporate research participation into broader efforts to improve their own and others' lives. They did not share the HIM study's emphasis on men's individual bodies as the key site of change to be monitored. Instead, they understood social bodies, at the levels of the couple, the family, the church, and the Mexican nation, as both metaphorical and literal entities that they could positively influence through men's participation in medical research. As middle-class research volunteers in a society intent on modernization but suffering from violent crisis, these couples incorporated men's HIM experiences into ongoing attempts to be "good" people and couples. They hoped to care for their families by raising children to emulate desirable gender and health behavior and to advance Mexican society by modeling modernity despite the chaos of narcoviolence and government unreliability.

Further, because they saw themselves as parts of these larger biosocial wholes, they expected their modern comportment and health behavior to actually improve the health of these collective bodies from within. This belief that men's HPV testing could have such far-reaching consequences depended on a collectivist understanding of human biology, which emphasized the effects that individuals' changes might have for group health and well-being. While the often highly educated study participants generally understood how human papillomavirus functioned in men's individual bodies, they cared more about its effects on what they saw as the collective biologies of the couple, the family, and a Mexican national body that they believed to be physically interrelated through a shared racial heritage.

This analysis also serves to develop the concept of collective biologies it-self. It extends the anthropologist Margaret Lock's foundational concept of "local biologies": the idea that human biology is not the universal assumed in biomedicine but, instead, context-specific and arising from "ongoing dialectic[s] between biology and culture in which both are contingent" (Lock 1993: xxi; Lock and Kaufert 2001). While careless applications of this concept risk reproducing biologically essentialist and scientifically invalid racial or class typologies (Meloni 2014; Niewöhner and Lock 2018; Yates-



Doerr 2017), applying it with appropriate nuance enables us to understand how the material and social aspects of varying histories and contexts differently shapes the development of human bodies (Brotherton and Nguyen 2013; Lock and Nguyen 2018)—including their assessment via medical screening (Burke 2014).

Here I extend this approach to examine a cultural factor that influenced the health behavior—and, thus, ultimately the local biologies—of medical research participants in Mexico. That factor is the idea that the "social body," a productive metaphor long used to understand societies (e.g., Scheper-Hughes and Lock 1987; Wilkis 2015), might not always be just metaphorical. In some cases social bodies are composed of literally biologically interrelated entities. I identify such units as collective biologies and provide a model for using that concept to investigate how people incorporate nonindividual understandings of biology into their health behavior and life choices. This approach extends a line of ethnographic work within the rubric of feminist new materialisms, which analyzes how people's lived experiences of emergent medical technologies serve as context-contingent sites for the coproduction of specific forms of biology and social life (Roberts 2016).

Thus, this book also extends the scope of social-science research on the experience of medical research participation. Studies of this arena have focused productively on the experiences of participants motivated by structural and social marginalization to enroll in shorter-term, medically invasive clinical trials (see, e.g., Fisher 2020). Here I investigate middle-class couples' simultaneously physical and social hopes for participation in long-term, longitudinal observational medical research that monitors rather than alters people's bodies. Most him participants were partnered with women, and couples often participated in joint decision making about enrollment. For example, many talked together with staff to understand the meaning of men's test results for both partners. To reflect this reality, and to resist beginning from the assumption that medical research participation was a fundamentally individual act, I took couples rather than individuals as my primary unit of analysis.

Love and marriage are key life arenas for living out both old and new social ideals and reproducing them through child rearing (Ahearn 2001; Hirsch et al. 2009; Hunter 2010; Povinelli 2006). Focusing on couples thus allowed me to investigate how people collaborated to incorporate men's research participation into shared daily life projects. This focus enabled analysis of the ways that people's efforts to live out local ideals of gender and race, which include assumptions that people are heterosexual and will reproduce,

influenced their experiences of and belief in the transformative possibilities of sexual health research. I found that romantic partnerships represented the innermost circle in the series of biosocial bodies that couples believed men's medical research participation could influence. In this book, I take these partnerships as my starting point for investigating the ways that people sought to incorporate study participation into collective biologies at the levels of the couple, the family, the church, and the nation.

My analysis shows that despite medical studies' framing as individual and exploratory, participants can understand them as treatment for simultaneously biological and social ills on the level of the social as well as the individual body. These findings extend the social-science insight that the "human subjects" who participate in medical research can, in fact, be very active agents and that the relationships in which they are enmeshed—with people, ideas, and economic and cultural context—fundamentally shape how they experience and make social use of research participation. Further, they make the new contribution of revealing how culturally specific ideas about the nature of these relationships—in the Mexican case, as simultaneously biological and social—influence people's hopes for, behavior within, and understandings of medical research participation. They also broaden the scope of our understandings of the consequences and possibilities for medical research and of the global landscape that has made it increasingly common. Most social-science work on this topic has investigated the experiences of poor and marginalized research participants. Here I examine how middle-class, heterosexual Mexicans who see themselves as the backbone of their society look to health research to treat social and biological ills simultaneously.

Given the central role that debates about good masculinities and femininities play in current Mexican discussions of modernity and race, my analysis expands our current understanding of research participation by focusing on its gendered and racialized aspects. I analyze the ways that middle-class participants hoped their self-consciously modern performances of health care, progressive masculinity, and modern marriage would enhance the well-being of broader biosocial wholes at multiple levels, from the couple to the Mexican social body. I show that they hoped to create change in two main ways. They sought to model ideally modern Mexicanness that would encourage others in the populace to engage in health-enhancing behavior. They also cared for their own physical health in ways they hoped would directly improve the health of the loved ones they slept with and cared for. These findings further reveal how in a context of national upheaval, medical



research participation became a way that people sought to be good citizens and lead their nation forward, in spite of government failings.

These insights can help us improve medical research design, analysis, and oversight. For instance, they demonstrate that participants' cultural ideas about biology and health directly influence both their desire to enroll in medical research and the potentially widespread biosocial consequences of that enrollment. These findings are key for research recruitment and ethics oversight. In addition, they can also help us think beyond business as usual in medical research. The design and assessment of medical research and public health projects would look different if individuals were understood as interrelated parts of a collective biology. In settings where people hold this cultural ideology, assessing exactly how they hope their own health behavior will treat others' ills can provide health workers with a guide for creating such change. Health researchers and public health workers can use participants' own ideas about how one's actions influence the biosocial whole as a model for both assessing and creating societal-level effects of individual health practice.

# Medical Research as Relational Experience

Medical research looks very different depending on the worldview of the person studying it. Medical research designers and regulators worldwide follow guidelines developed out of the 1978 U.S. Belmont Report as they engage with research participants. The Belmont Report was a response to prior abuses, such as the Tuskegee syphilis study and Nazi experimentation, intended to identify ways to protect the "human subjects" of medical research. As such, the report and the concept of participants as "subjects" frame researchers as actively protecting or harming people, who more passively respond to research experiences. The report's findings also reflect specifically Anglo-American cultural ideas about the nature of personhood that have spread around the world along with the globalization of medical research (Petryna 2009; Stark 2011). The report understands "human subjects" as "autonomous agents," reflecting American ideals of independence and individuality by defining respect for people's autonomy as the ability to freely make decisions on their own (Sims 2010). A key aim of regulation in this model is to avoid the "therapeutic misconception," in which people confuse the aims of medical research with the aims of clinical care and believe that studies are designed to treat them rather than generate knowledge (Dresser 2002). From this perspective, the only safe and legitimate reason

for participating in research is the altruistic desire to help the unspecified others who might benefit from scientific advances, rather than to directly benefit oneself or one's loved ones (Montoya 2011).

However, social-science researchers who investigate how people's diverse contexts influence their research experiences have shown that this individualistic and biologically focused view is often inaccurate. For example, it fails to account for the fact that many aspects of identity that participants see as central to their experience of research—such as gender and one's place within a family—are developed through interactions with others (Sariola and Simpson 2011). An individualistic focus obscures how participants' interpersonal relationships mediate clinical outcomes—for instance, by influencing how participants comply with study protocols (Scott et al. 2011). It also takes for granted the American cultural notion of autonomy as individuality, which does not apply in societies where people value collaborative decision making with others. For instance, deciding jointly that Arturo would participate in the HIM study was central for his and Ade's experience, providing a way for her to share in and support his lifestyle change. While critical feminist bioethicists have long called for attention to the relationality inherent in participants' decision making officially idealized as "autonomous" (Meynell and Borgerson 2020; Sherwin 1998: 19), consent processes that attend to such lived relationality remain experimental and marginal to institutional bioethics oversight of medical research (cf. Ramabu 2019).

Nevertheless, research reveals that, in contrast to the assumption of "human subjects" experiences as individual and impersonal, people worldwide often use participation in clinical trials to pursue wide-ranging social ends (Fisher 2013). For instance, participation can be a way to assert desired attributes such as respectability, virtue, selflessness, or expertise to others (Black 2019; Dixon and Tameris 2018; Stadler et al. 2018). This aim can be woven into the broader moral projects of daily life beyond the clinic, such as quitting stigmatized behavior such as smoking (Wolters et al. 2014). Thus, people can assert specific identities through participation in medical research. This is similarly true for participation in other forms of health surveillance, such as screening programs (Armstrong 2005, 2019).

People may also forge new kinds of relationships through research participation that reflect and respond to the forms of inequality that shape clinical trial worlds (Fisher 2020). Forming and maintaining bonds of trust between researchers and participants is necessary for the research process (Compaoré et al. 2018; Thabethe et al. 2018). Yet these relationships can range much more widely, from participants' reconceptualizations of researchers



as caregivers (Leach and Fairhead 2011; Reynolds et al. 2013) to the creation of new study-based communities and forms of kinship (Geissler et al. 2008) that can persist long after experiments end (Nguyen 2015). Medical research participation can be an active site for the creation of new social forms and cultural meanings, such as affiliation with political subcultures (Abadie 2010) or new forms of valuation (Swallow et al. 2020). It can serve to create and relate people to life-shaping identity categories such as racial or ethnic labels (Epstein 2008a, 2008b; Valdez 2019). Participation can also be a site for advocating for attention to marginalized groups' concerns and for staking broader rights claims (Epstein 1996).

The anthropologist Susan Reynolds Whyte (2011: 49) thus argues that, to fully understand this aspect of human experience, "We should be asking how relationships are developed, expressed and mediated in medical research." This makes sense, given the findings discussed above and the fact that, despite the American cultural fixation on individuality, people's daily life experiences of making ethical choices include consideration of how their actions will affect others' interrelated social and physical futures (Al-Mohammad 2010; Csordas 2008; Weiss 1999). Indeed, providing biological or experiential data for medical research can be part of a broader, daily life process of making meaning and seeking to do right within one's interpersonal relationships (Sheikh and Jensen 2019).

Since sexual reproduction so obviously requires human interaction, clinical trials of contraception highlight how people's research experiences actually depend on their relationships. While the effects of medical research participation on gender are rarely studied, two scholars have shown that clinical trials can be sites in which people collaborate with romantic partners, and even researchers, to construct and perform ideals of gender and love. Nelly Oudshoorn's (2003) research on studies of oral contraceptives for men revealed that participants, their female partners, and study researchers understood the project as affecting the couple as a whole, given the risk of pregnancy. Further, female partners and researchers collaborated to frame male pill testers as performers of simultaneously adventuresome and progressive masculinities. Similarly, Catherine Montgomery's (2012) analysis of women's experiences in a microbicide trial showed that, while study designers imagined subjects gaining autonomy thorough confidential contraceptive use, participants themselves worked with their partners to use the technology to pursue shared sexual benefits and to strengthen their romantic relationships. These examples highlight that relationships with other people (such as spouses) and with elements of broader context (such as gender ideals) fundamentally influence participants' actions and experiences of research. They further show that participants might understand medical research as affecting their embodied relationships rather than just their individual biologies.

Participants' relationships to the structural aspects of their context the economic and political setting that determines the conditions of their daily lives—also fundamentally shape their experiences of medical research. Qualitative research shows that participants might see their relationships with study staff as economic exchange or labor, as they trade bodily substances for care or compensation (Alenichev and Nguyen 2019; Cooper and Waldby 2014; Fairhead et al. 2006; Nguyen 2015). This is quite different from the regulatory ideal of participating for altruism rather than personal gain. Yet it reflects the fact that making decisions without constraint is a privilege that few people have in an unequal world. Economic need and the widespread harms faced by members of marginalized groups influence people's decisions to participate in medical research (Gaut 1995; Montoya 2011; Towghi and Vora 2014). For instance, in contexts where international nongovernmental organizations are key sources of employment, research participation can thus be an entrepreneurial act in which people balance fears of exploitation with hopes that it will offer new economic opportunities with trial sponsors (Bruun 2016). Further, when people lack money and access to care the so-called therapeutic misconception that medical research delivers health care might not be incorrect after all. While medical research is not intended to improve participants' health, it sometimes offers the only health screening or care people can get (Fisher 2008; Molyneux et al. 2005; Montoya 2011; Reynolds et al. 2013; Waldby 2012).

This phenomenon is especially powerful as medical clinical trials increasingly enroll poor and marginalized populations worldwide. Members of such groups often rely on participation for income or basic health care (Elliott and Abadie 2008; Farmer 2002; Fisher 2008, 2013; Geissler 2013; Kamat 2014; Nguyen 2009; Petryna 2009). This reality is generally unacknowledged by local Institutional Review Boards that follow the American focus on individuals abstracted from context (Simpson et al. 2015), even if participants and local research workers are quite aware of it (Rayzberg 2019). Structural context matters for even economically stable participants' experiences, as with Ade and Arturo's experience of violent insecurity that made HIM participation attractive. It also shapes study staff members' motivations as workers, as they might hope to aid their communities by securing international support for local industry and infrastructure (Genus 2018). In light

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of these relationships, some scholars call for understanding research projects and the communities that host them as intertwined systems rather than separate entities (Wyss-van den Berg et al. 2020).

These dynamics of interdependence occur in other situations in which entities from the global North seek data from groups that lack resources. Lauren Carruth (2018) demonstrates this in the case of data collection by international humanitarian organizations in the Somali region of Ethiopia. There, potential beneficiaries of aid and local data collectors develop evolving strategies for seeking support from humanitarian "audit culture" itself, which include attendant changes in their forms of interaction and presentations of self. These power-laden relationships among aid organizations, local workers, and research participants/potential beneficiaries fundamentally shape the design and interpretation of health research studies, as well (Biruk 2011, 2018).

By investigating the ways that HIM participants and their partners' relationships to people and their contexts influenced their medical research experiences, I follow Sassy Molyneux and P. Wenzel Geissler's call to understand research participants' experiences holistically rather than individualistically by examining them at different "levels of scale" (Molyneux and Geissler 2008: 687). These levels span the interpersonal and the societal, in an approach that, Geissler (2011: 6) writes, "destabilizes taken-for-granted boundaries" in the study of medical research participation by refocusing the object of inquiry beyond the individual participants' biologies and experiences. This approach builds on the fundamental medical anthropological insight that health experiences cannot be fully understood without analysis of how they affect a person's physically felt body; social relationships; and interactions with laws, policies, and other aspects of social structure (Scheper-Hughes and Lock 1987). In the case of medical research, attending to multiple levels of scale enables study of how participants' research experiences fit into the rich webs of physical and social interactions with people, cultural ideologies, and structural contexts that make up their lives.

In this book, I investigate the ways that HIM participation matters for people's embodied relationships at the levels of scale that they cared about most. My analysis traces how HIM participants and their partners made men's HPV testing matter at the levels of the couple, the family and church, and the Mexican nation. Analyzing the HIM study experience at multiple levels of scale enables me to faithfully capture couples' experiences of participation as nonindividual and as both socially and physically consequential for the collective biologies to which they belonged. My goal is to provide a

holistic rather than individualistic view of the complex reasons that men participated in the HIM study, and of the wide range of collective biosocial benefits they and their partners sought, on the various levels of scale that came to matter in this Mexican context. I hope that this analysis will provide a model for understanding the concrete consequences of medical research participation for collective rather than individual bodies, which medical research designers and regulators can use to broaden their ideas of harms and benefits from the individual "human subject" to the participant's physically and socially interconnected world.

# The Setting

### MESTIZAIE AND IDEAS OF THE MEXICAN SOCIAL BODY

People's hopes that their individual participation in the HIM study would have widespread benefits draw implicitly on an ideology of collective "Mexicanness" embodied in the concept of mestizaje (mixing). In Mexico, it is commonly believed that Spanish conquest of Indigenous peoples began a process of racial mixing that would beget a racially and culturally unique mestizo (mixed) population. Governments since conquest have promoted engagement in the behavior and body practices desired by elites as ways for people to shed Indianness and assimilate into more privileged racial categories aligned with whiteness and Europeanness (Alonso 2004; Knight 1990). Postrevolutionary federal programs and public intellectuals then fused ideologies of mixing with nationalism to promote biological and cultural homogenization into an idealized mestizo populace imagined to be ideally suited for citizenship. These efforts popularized the idea that the Mexican social body is interrelated in two intertwined ways: through a shared racial heritage of ethnic mixture, and through a common societal aim of evolving toward the ideal behavioral expression of that mestizo identity.

This ideology of race conflicts with the anthropological view that the concept of race is not scientifically valid. Anthropologists argue that there are no essentially biologically different human groups, and the biological variation among people assigned any racial category is just as great as the variation between people assigned to different categories (Fuentes et al. 2019). Instead, we argue that race is a cultural ideology with immense power to affect people's lives and, in turn, their bodies. It is from this perspective that I analyze the ideology of Mexican mestizaje as an element of cultural context that shapes HIM participants' experiences.

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Currently dominant ideas about race in Mexico continue to reflect revolution-era takes on this notion of mestizaje. The Mexican Revolution (ca. 1910–20) entailed complex interactions among varied political factions representing diverse groups and forged new national political and cultural ideologies. It ushered in a new constitution in 1917, marking an era in which the goal of government was reconceptualized as serving the needs of a national population imagined as a cohesive whole. Politicians and public intellectuals promoted of a specific kind of Mexican mestizaje as part of efforts to create a homogeneous, governable, and modern national populace in this new political landscape (Alonso 2004; Manrique 2017).

José Vasconcelos, minister of education in the early 1920s, most clearly articulated this vision in his notion of Mexicans as la raza cósmica. He asserted that Indigenous and European populations present in Mexico would mix over time into a "cosmic race" ideally suited for modernity (Vasconcelos [1925] 1997). He and his contemporaries promoted this ideology widely. For example, Vasconcelos supported the famous Mexican muralist movement comprising painters such as Diego Rivera, which romanticized indigeneity but framed it not as an end goal but as a contributor toward a mestizo future (Manrique 2016). This ideology also extended and influenced Mexican eugenicists' efforts to frame hybridity, rather than "purity," as the racial trait that would produce more biologically and socially fit populations (Stepan 1991). The idea that a cohesive Mexican social body was coming into physical and social existence, and that it could be strengthened and advanced by disciplining Indian bodies and behavior into whiter, mestizo-identified comportment, has been represented in literature and promoted in schools for over a century (Janzen 2015; Sierra [1900] 1969; Vaughan 1997; Vaughan and Lewis 2006; Walsh 2004).

This idea that racial mixture combined with ideal behavior could create a better population has animated national public health projects from the revolution through today. Government health programs have framed health practices as ways to embody modern mestizaje, behaviorally and—through the effects of that behavior on the body—biologically. These efforts have also emphasized the performance of ideal gender norms as key to health, modernity, and the creation of new generations who would embody these traits (González-Santos 2020). For example, twentieth-century health campaigns sought to teach parents to rear children who would form the new, ideal population (Stern 2003). Framing families as microcosms of both nation and "race" has been a common way to align embodied practices of

gender with emerging societal-level goals, while often perpetuating foundational inequalities (see, e.g., Pirinjian 2019; Stoler 1989). Mexican visions of the "revolutionary family" tasked women, as mothers, with physically and morally nurturing future citizens by instilling hygienic behavior in children (Stern 1999) and men, as fathers, with transmitting state goals to their families while eliminating unhealthy and unproductive behavior coded as Indigenous, such as binge drinking (Bliss 1999; Joseph et al. 2001). Physicians even predicted that mestiza women's pelvises would reach an ideal midpoint between too-narrow European and too-wide Indigenous structures, reflecting stereotypes about each group's femininity and the kind of womanhood that would enable national progress (Cházaro 2005). These racial ideologies and gendered expectations of women's responsibility for the healthy reproduction of the nation have become intrinsic to the Mexican state and its systems (Sue 2013). They now underlie representations of the Mexican population, from federal genomic health research (Saldaña-Tejeda 2018a) to the national forensic database (Nieves Delgado 2020) and pornography (Mezo Gonzalez 2018).

They also fuel persistent, racialized inequalities. Such ideologies of mixing have created and reinforced the racial categories understood as the base components of mixture (Wade 2004). For example, the category of "Indian" resulted from the homogenization of diverse pre-Columbian societies into one subjugated group amid conquest. It is an inherent driver of racialized inequality and marginalization. Given this context, the varied ideologies of mestizaje that emerged throughout post-conquest Latin America have always framed "Indian" and "European" (and, in some cases, "African") as discrete racial groups that all mix together but are unequally valued in a process of homogenization hoped to entail physical and behavioral whitening (Chaves and Zambrano 2006; Stepan 1991; Wade 2004).

This is true even for utopian visions of mestizaje. Vasconcelos ([1925] 1997) wrote about racial mixing as a move toward a fully intermixed, ideal, and thus equal population. Yet efforts to promote Mexican mestizaje have always centered a Europeanized or whitened mestizo as the emblem of modernity and, in the process, have both perpetuated and concealed systemic, racialized inequalities (Manrique 2016). This powerful ideology of mestizaje is dominant enough to write out the presence of populations who identify with heritage other than the Indigenous and European components thought to contribute to la raza cósmica. For instance, government genetics programs currently define the "Mexican population" as mestizo (López-Beltrán and Deister 2013). The category of Afro-Mexican was added to national

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government population surveys only in 2015, following activists' efforts to challenge dominant narratives about the nation's racial composition (Love 2015; Vaughn 2013).

Thus, I interpret urban, non-Indigenous research participants' frequent use of the term "Mexican" to discuss their own identities and natures as indexing this culturally ubiquitous understanding of "Mexican" as mestizo/a. When I discuss mestizaje as an implicit conceptual underpinning for participants' explicit narratives of their medical research experiences, I am also acknowledging their favored position within a national system of racial hierarchy that oppresses Indigenous people and others who do not culturally or phenotypically match elite visions of mestizo Mexicanness. Like whiteness in the United States, claiming the identity of "Mexican" provides social privilege, as this is understood to be the default, "normal," and ideal category of personhood by those with the most social power (Moreno Figueroa 2010).

Yet unlike North American notions of whiteness, the category of mestizo refers to an always ongoing process rather than a static, essential trait or group. First, the notion of racial mixing toward perfection imagines a future in which race will cease to exist, as everyone is mestizo. So while there are still "Indians," the process of mestizaje is incomplete. Importantly, it always will be, since, as mentioned earlier, ideologies of mestizaje also continually reproduce the racial categories understood to be the components of mixture (Wade 2004). Second, race in this framework is both biological—an essence transmitted through ancestry—and, even more important, behavioral. As I show, HIM participants' narratives about their responsibility to a social body reflect how mestizaje works as an aspirational and ongoing body project.

Thus, having lighter skin is just one way to access privilege. People can also claim mestizo status by acting in ways classed as modern (implicitly, oriented toward Europeanness or whiteness) versus "traditional" (explicitly, Indian) (Perez Lopez 2017). While Latin American countries have different national racial ideologies, throughout the region whitening and belonging in privileged racial categories is attainable through behavior (de la Cadena 2008), including health behavior (cf. Roberts 2006). Interventions such as the Mexican public health and education campaigns discussed earlier have long fostered the belief that individuals' actions can define them as either "decent people" or not; decent meaning mestizo rather than Indian, middle versus lower class, and respectable versus disreputable (Hind 2017). So mestizaje is something one does, by embracing current cultural ideals of modernity and rejecting stigmatized behavior associated with indigeneity. Further, it is

something one does in the name of the collective social body. The idea that anyone in Mexico can join the racial category of mestizo through "modern" behavior, and should do so to advance the nation, enables discrimination against Indigenous-identified and darker-skinned people to be dismissed not as racism, but as the consequence of those people's own failure to assimilate (Moreno Figueroa and Saldívar Tanaka 2015; Saldívar 2014).

For example, implicitly mestizo-identified health workers often critique patients' behavior and self-presentation they see as antimodern, unhygienic, or backwardly Indigenous (Gutiérrez Chong 2017; Smith-Oka 2012). As with the broader discourse of mestizaje that reifies the racial categories it purports to supersede, medical education in Mexico fuses stated ideals of providing care for the nation with systems that reinforce providers' privileged class and racial status relative to the public service users who provide raw material for their training (Smith-Oka and Marshalla 2019). Thus, in Cuernavaca, government health workers often place the blame for poor and less-educated people's failure to perform preventative health care on an implicitly Indian or low-class "culture of ignorance" that they, as more educated citizens, have the duty to combat (Schneider 2010). Health campaigns continue to target antimodern behavior framed as the product of Indigenous or lower-class cultures while obscuring state failures to reduce the poverty and inequality that most significantly determine health opportunities (Soto Laveaga 2007).

In keeping with that emphasis on personal behavior as the key to national modernization, middle-class mestizos often cast their own sociomedical practices as ways to promote progress in the social body and offset the negative contributions of Indigenous or low-income others. For instance, Lara Braff (2013) found that non-Indigenous fertility clinic patients in Mexico City engaged in "reproductive othering." They criticized rural, Indigenous, and poor women for contributing to overpopulation and transmitting backward cultural views. In contrast, they and their physicians justified their own efforts to reproduce by framing themselves as prepared, modern, and implicitly whiter than those imagined others. Their use of medicine as an arena for such assertions makes particular sense since Mexican medical systems—especially specialties related to reproductive health and pediatrics—were developed to deliberately improve and modernize the national populace (González-Santos 2020).

This use of assisted reproduction to assert elite status and imbue a next generation with it demonstrates the processuality inherent in Mexican mestizaje. As the presumptive progeny of Indigenous and European ancestors,

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members of this group can act in ways that are more closely aligned with the imagined characteristics of either racial pole, facilitating or thwarting the embodied and cultural whitening over time in the Mexican social body. Thus, while projects promoting gender and health modernities to facilitate governance have been common worldwide (see, e.g., Adams and Pigg 2005; Briggs 2002; Hunt 1999), in Mexico they have reflected and reified the ideal of a population moving toward increasing biological and cultural homogeneity. Practices of ideal gender and health behavior are thus ways of aligning more and more with modernity over time in the service of developing a national, mestizo collective.

This racial ideology also profoundly influenced HIM participants' experiences. Their hopes that men's research participation could benefit broader biosocial bodies drew on the idea that Mexicans as mestizos share a unique biological and cultural essence that, if lived out well, could advance the Mexican race and nation. It is important to note that participants did not speak of themselves as mestizo, as is typical of members of a dominant and culturally unmarked racial category. Instead, they frequently and selfconsciously referred to themselves as "Mexican." Given the pervasiveness and longevity of the ideology of mestizaje, I interpret self-identification as Mexican during discussions of population modernity or ideal behavior as drawing implicitly on the beliefs discussed earlier. This is not to say that all participants supported such a vision of Mexicanness, could articulate histories of its construction or promotion, or thought consciously about it. Instead, I argue that the common pattern of participants' referring to themselves and others as "Mexican" to explain their characters, bodies, and behavior drew meaning from this shared cultural history regarding the nature of "Mexicanness" as mestizaje, albeit in implicit and varied ways. They used the term especially to reference the ambivalence inherent to concepts of Mexicanness: that it entailed both innate urges toward backward behavior and the behavioral possibility of advancing beyond it.

This was evident in Arturo and Ade's understandings of what Arturo's study participation could achieve. The couple felt that the study was beneficial to them specifically "as Mexicans." Both saw preventative health care as valuable but said that they suffered from what they saw as an innate cultural predisposition to avoid it. Discussing how their efforts to eat healthily were hampered by Arturo's periods of unemployment, and the cheapness and temptation of tortillas and rice, Ade she said that failing to care for one's health was "the idiosyncrasy of this country." She explained, "We're

lazy, right? As Mexicans, we're more about correcting than preventing.... We're not very farsighted." They discussed HIM participation as a way to work against this instinct.

I argue that the rhetorical choice to frame these problems as issues inherent to Mexicans draws clearly, if implicitly, on the ideology of mestizaje discussed earlier. Mestizaje is never a completed project. It must be accomplished by ongoing rejection of the backward, implicitly Indigenous tendencies within one's mixed constitution. Such rejection requires behavioral alignment with an implicitly whiter, modern future. Further, it is a set of individual choices culturally framed as reflecting and affecting the evolution of the Mexican populace.

For Ade, to be Mexican is thus to be innately pulled in both progressive and regressive directions. Her ongoing efforts to act in modern ways—for example, by engaging in preventative health care—demonstrate privileged racial status on the individual level and hold the promise of moving the populace as a whole forward on the imagined continuum toward realizing the potential of la raza cósmica. This ideology was typical of HIM participants who saw themselves as predisposed to regressive behaviors because of their Mexicanness, as well as made vulnerable by the Mexican nation's economic failings, but also understood actions such as research participation as a way to begin with themselves to create change in the social body and help their nation advance. Throughout this book, I investigate the ways such hopes motivated medical research participation.

# Gender in the Social Body

As demonstrated by the foci of national public health projects, gender norms have been closely linked with cultural visions of ideal Mexicanness. While women have been tasked with demonstrating ideal mestiza femininity to raise modern and healthy families, men have been simultaneously feared to reflect the worst of Mexicanness and exhorted to embody its best. The *macho* form of masculinity stereotypically identified with Mexican men developed out of revolutionary-era political and media rhetoric linking the essence of the new Mexican nation to a tough and respectable but violent form of masculinity (Alonso 1995). The notion that Mexican men share an innate *machismo* has become culturally ingrained since the 1950s and persists, despite critiques that themselves have been widespread since the 1990s (Gutmann 1996). With the internal complexity and conflict that characterizes most cultural ideologies, this trait is attributed simultaneously to the notion



that mestizo men's conquistador ancestry made them innately predisposed to womanizing, violence, and emotional withdrawal and that their Indigenous ancestry inclines them to forms of social backwardness, including in their styles of masculinity (Melhuus 1996; Paz [1961] 1985).

Thus, machismo is a cultural idea rather than an accurate descriptor of most men's identity. Nevertheless, it remains a central way that Mexicans understand masculinities (Domínguez-Ruvalcaba 2007; McKee Irwin 2003). Machismo has long and fiercely been critiqued as a barrier to national advancement and gender equity (Amuchástegui Herrera and Szasz 2007; Gutmann 1996; Ramirez 2009). Today, the term "machismo" is seen as negative even by male gang members who value violent toughness alongside specific forms of protectiveness and care (Sverdlin 2017). Even as male violence is increasing in a context of economic inequality and insecurity that makes forms of care such as breadwinning increasingly difficult to perform (Gamlin and Hawkes 2017), men and boys from varied walks of life critique what is now seen as a problematically "traditional" form of manhood (Singleton et al. 2018). These contradictions reflect simultaneous challenges to and maintenance of Mexican gender stereotypes (Galeana and Vargas Becerra 2015) within a context that the sociologist Gloria González-López (2015: 20) calls "a changing and unpredictable patriarchal collage."

Yet these common critiques of machismo still often frame it as a natural attribute of Mexican men. In contexts from antiviolence classes to medical care, people call for men to struggle against their presumptively innate tendencies toward violence and womanizing (Amuchástegui Herrera 2008; Wentzell 2013). This idea of an inherently problematic Mexican masculinity is also continuously revitalized by discourses about Mexican womanhood. Women's claims to rights often invoke rather than disrupt ideals of femininity forged during the Mexican Revolution, which fuse even earlier emphases on domesticity with valorization of toughness and resilience. Women's strength and participation in the public sphere are made palatable via emphases on mothering, caring for one's family, fidelity, and the ability to *aguantar* (suffer through) adversity, including that dealt by macho men (Haney 2012; Melero 2015; Melhuus 1996). Thus, even as people decry machismo, they keep the concept alive by framing their own behavior and experience in relationship to it (Gutmann 1996; Ramirez 2009).

Alongside this enduring assumption about Mexican men's problematic nature, new ideals of marriage and masculinity have emerged. In Cuernavaca, gender roles and relationships have become more egalitarian over the past several decades (LeVine 1993). Critiques of machismo and calls for

"modern" gender norms are now common. They include calls for the increasingly globally popular experience of "companionate marriage." This is a self-consciously modern form of marriage centered on love, intimacy, and mutual pleasure rather than economic production or biological reproduction (Hirsch 2003; Padilla et al. 2007; Wardlow and Hirsch 2006). While strong and lasting extended family ties have long been a Mexican cultural ideal, people now often emphasize love and the ability to develop personally within a supportive nuclear family structure as key to the maintenance of such bonds (Nehring 2011). Yet it is important to note that companionate forms of marriage and masculinity reconfigure, but do not erase, gendered forms of hierarchy and power (Shakuto 2019). While for some companionate marriage represents a modernization of gender roles in comparison with a "traditional" past, and may also represent modernity in that same-sex marriage is now legally recognized throughout Mexico, it is also a subject of activist critique as an institution that upholds antiquated forms of gender, sexual, and social organization and the economic arrangements on which they rest (cf. Russo Garrido 2020).

The currently dominant ideal of companionate marriage in Mexico also reflects preexisting racial hierarchies. Specific ideologies of marriage have long been associated with modernity and mestizaje, but their content has changed over time. At one time, having separate spheres for women and men defined families as mestizo rather than Indigenous (Browner 1989). Now, companionate marriage exemplifies visions of modernity associated with *blanqueamiento* (whitening), which reject machismo, separate spheres, and emphasis on reproduction in favor of a focus on couple's intimacy (Ramirez and Everett 2018).

In practice, people today widely desire what researchers call companionate marriage, but they understand it diversely. Such notions of good marriage vary from explicitly feminist egalitarianism to coupling respect for women with the maintenance of patriarchy. Yet whatever gender expectations people have for their own marriages, they usually define them in contrast to "traditional" forms of marriage and masculinity, which they frame as barriers to both national modernization and personal fulfillment (see, e.g., Wentzell 2013).

While emphasis on successful provision has remained central to understandings of positive manliness in Mexico and elsewhere (cf. Smith 2017), ideals of men's responsibility have broadened to incorporate provision of care and intimacy, including care for one's self through health behavior

(Amuchástegui Herrera and Szasz 2007; de Keijzer 2016; Gutmann 2007). A masculine ideal that I call "companionate responsibility" has developed, characterized by domesticity, fidelity, and self-care, as well as responsible provision (Wentzell and Inhorn 2014). Living out this currently ideal form of modern masculinity amid the economic and social constraints of life today has become a key "moral project" for many Mexican men (Yarris and Ponting 2019: 39). This ideal bridges the provider aspects of prior ideals for husbands and fathers with the emphasis on emotional closeness central to companionate marriage. It is highly visible in Cuernavaca. For instance, local antiviolence protests have been led by a model of engaged fathering: the poet Javier Sicilia, who began to organize in response to his son's murder (Padgett 2011). As in other Mexican cities, people's responses to violence often include critiques of "traditional" masculinities, from criticism of violencia machista (macho violence) to attempts to reform men but maintain patriarchal structures among the growing population of evangelical Christians in the city (Brito 2016; Haney 2012).

Companionate marriage and responsibility were what Arturo sought to better embody when he promised God that he would improve as a husband and father. Our interviews served as one of many daily life sites for he and Ade to engage in emotional intimacy. They were physically demonstrative and emotionally engaged as we talked—quick to laugh together and to touch the other's leg or hand when discussing difficult times. They had valued emotional connection from the start, telling me that from the time they met as teenagers, each had been attracted to the other's kindness and the ways their partner helped others. For instance, Arturo said that Ade "doesn't know how to be harsh" and "helps almost everyone," counting off a list of the neighbors, friends, and coworkers she had supported. She saw his dedication to his church peers and the HIM study as similarly valuable. They also agreed that they had, in his words, "matured" together during their twenty-six-year relationship. Ade attributed this to deliberate, joint engagement in self-improvement. She said, "We've grown a lot together. Each of us on our own has taken courses in humanism, personal advancement, psychology." She added that Arturo's religious conversion "has really nurtured his life, his character, his behavior. Although he was always kind, calm, caring, attentive, home-bodied—that increased." Laughing, she said that she herself used to be more controlling and quick to anger but had calmed in response to Arturo's changes: "If he didn't explode, well, I didn't either, since I didn't have anyone to yell at." He said that over time they have changed

as a couple and as parents, becoming more tolerant and trusting of family members' desires and interests. This emphasis on shared emotional growth lies at the heart of contemporary Mexico's companionate ideals.

## INSECURITY AND PUBLIC HEALTH IN CUERNAVACA

Cuernavaca was an ideal site for this study since, beyond housing the HIM study, the city is a microcosm of many of the key social histories, changes, and problems facing Mexico. The capital of Morelos State, located eighty-five kilometers south of Mexico City, Cuernavaca is a former elite vacation site where colonizers' summer palaces now serve as tourist attractions. For decades the city has experienced rapid growth marked by economic inequality (Aguayo Quezada et al. 2014). The metropolitan area now contains more than 900,000 people (Consejo Estatal de Población de Morelos 2013). This includes a diversity of largely mestizo-identified residents: affluent bedroom communities of Mexico City workers, families who migrated in the 1960s to work in emerging industrial zones, and residents of once-rural towns absorbed in the sprawl. Cuernavaca's poverty rate is low relative to the rest of the nation yet still painfully high at 26.5 percent, with the vast majority of the population identified as vulnerable to economic want or deprivation of social services (CONEVAL 2012).

The once-peaceful metropolitan area has also entered a dramatic security crisis. Over time the violence that represents the "dark side" of maintaining a stable yet corrupt federal government has affected new areas of the country (Pansters 2012: 8). Fallout from the intensification of the federal drug war of the early 2000s destabilized the established patterns of corruption and criminal turf control that had meant safety for everyday people in Cuernavaca (Knight 2012; Melgar Bao 2005). In 2009, a cartel turf war generated a crime wave that eventually led the metro area to become one of the highest-crime sites in the country (Miranda 2012; Pastrana 2011; Seguridad 2012, 2015). Rates of extortion, violent robbery, and kidnapping for ransom have skyrocketed since the mid-2000s (Aguayo Quezada et al. 2014; Seguridad 2015).

This insecurity has been intensified by a feedback loop between criminal violence and the ravages of the global economic crisis. Together, these factors sharply curtailed the construction and tourism jobs that had been critical to the local economy. In a local version of a growing national trend, the formerly ubiquitous crowds of American college students studying Spanish in Cuernavaca have disappeared from the streets. (See also Luna 2018 for a borderlands example.) This situation is worsened by the fact that the zone's youthful population, with about half of residents age twenty-nine



or younger, is suffering from lack of employment and educational opportunity (Peña González 2014). As on the national level, in Cuernavaca political corruption has precluded an effective response to these linked violence and economic crises. Morelos State was recently rated as the second most corrupt in the nation in a national assessment (Aguayo Quezada et al. 2014). As a result, almost no Cuernavacans say they trust public institutions such as the police force (Peña González 2014).

Arturo's carjacking made him one of many victims of this situation. His response of religious conversion also appears to be common. Evangelical Christianities, locally glossed as *Cristianismo*, are increasingly visible in Cuernavaca. For example, one congregation built the city's first American-style megachurch during my research for this book. While statistics are not available to indicate whether conversion has increased in response to recent insecurity, discourses about conversion in Cuernavaca reflect ongoing critiques of machismo, economic inequality, and violence, offering religious practice as a way to counteract and heal from social problems.

While they express it in diverse actions that range from religious to medical practice, Cuernavacans of all social classes report changing their behavior in response to the rising crime (cf. Tonantzin 2013). Surveys show that the majority of residents have curtailed daily life activities such as going out at night, going out alone, and using public transportation (Aguayo Quezada et al. 2014). People have also become despairing of the notion that collective solutions might arise. Although activism is visible in the city—for example, in marches organized by the Catholic Church against government corruption and violence (*La Redacción* 2016)—few people think that those in their neighborhood or community would organize to address political, social, or health problems (Aguayo Quezada et al. 2014). Instead, like others faced with navigating the "routinization of violence" in Latin America (Davis 2018), people have attempted to adapt their behavior to survive these new and frightening circumstances. This book explores how people have incorporated their involvement in the HIM study into such responses, showing that even as people lose hope in government aid or collective action, they still hope to heal the collective through their own actions. Beyond simply trying to stay safe, HIM participants often came to see the study as a way to live out and promote responsible, caring, and modern behavior that they hoped would provide a counterpoint to the societal dissolution happening around them, and thus help to heal the social body.

Cuernavaca's health services infrastructure figured into these hopes. While people voiced disgust for politicians, they also believed the government should

live up to postrevolutionary promises of care for the people. These promises were reflected in the city's public universities, research centers, and hospitals from which people sought services even as they dismissed other areas of the government, such as the police and judiciary. The HIM study was based in the regional hospital of the IMSS, a federal entity that offers free health care to all privately employed workers as one of many projects intended to foster modern, healthy mestizo families. Many of its workers and patients became HIM participants, seeking to further the system's goals in both their research participation and daily lives. For instance, as an IMSS nurse, Ade believed that she was duty-bound to promote comprehensive visions of health within and beyond her formal job requirements. Frustrated by the cursory sexual health education she saw her daughters receive as teens, she took training as a sexual educator and sought information about HPV from the HIM staff. Hoping to "plant a seed . . . to prevent a little," Ade gave formal talks at schools and used the brief breaks in her busy IMSS workdays to waylay teens waiting for medical services and "offer them information about prevention," such as condom use.

The fact that there are teens waiting for hours at the IMSS clinic demonstrates another key aspect of the public health system: in Cuernavaca and elsewhere, its goals are undercut by underfunding and government unreliability. The IMSS and other social security organizations reflect a history of governments that have ruled by selectively providing services amid widespread corruption. While the postrevolutionary Mexican state has always faced challenges from both disenfranchised groups and organized crime, it has maintained greater stability than many other Latin American countries by coupling repression and criminal alliances with very real (if unequally distributed) efforts to provide health and social services in keeping with citizens' constitutionally mandated rights (Knight 1992; Matsuura 2013). Megan Crowley-Matoka (2016) calls Mexico a "slippery State," in which citizens expect aid but cannot predict, in any particular interaction, whether they will meet with competence or corruption, disorganization or resource scarcity. She describes state institutions as "widely understood to be at once a source of vital resources (such as health care) and profoundly corrupt" (Crowley-Matoka 2016: 126). The IMSS itself is both credited with a major role in increasing the population's life expectancy and critiqued for chronic underfunding and uneven quality and availability of services (Moreno et al. 2009; Notimex 2014).

Yet while Mexican citizens overwhelmingly view politicians and government institutions as corrupt and ineffectual, they tend to call not for privatized



alternatives but for a rehabilitated state to meet its mandate of caring for its citizens. Citizens have previously responded to state failures to provide reliable protection and care by protesting and by forming community organizations to offer the services that the state promotes but often fails to provide (Schneider 2010). Today, IMSS workers and beneficiaries are actively protesting against recent government reforms that incorporate elements of privatization (see, e.g., Lopez 2015). Overall, beneficiaries tend to see the IMSS as an imperiled but important vestige of a revolutionary federal commitment to the public good, which might not be reliably efficient or trustworthy but should be bolstered rather than dismantled (Crowley-Matoka and Lock 2006).

Simultaneous commitment to the IMSS and its goals, and frustration about the availability of its services, influenced many people's decisions to participate in the HIM study. This was the case for Arturo and Ade, who learned about HIM through Ade's IMSS job; they believed the study was trustworthy because of its association with the IMSS, but they also enrolled Arturo in part to access more responsive health services. Ade noted that as an IMSS worker she could get medical testing whenever she needed by using her social connections in the hospital. Yet while Arturo had access to cost-free IMSS care, to use it he would have to face what Ade described as the "lines and lines and lines of people" always waiting. They saw his HIM participation as providing more responsive first-line care because, as Ade noted, "It's a complete study," as well as the only local site where men could be tested for HPV. Arturo saw his clinical visits as "practical, quick and secure." Further, the intimate testing was done with "so much trustworthiness, so much hygiene and so much ethical commitment" that Arturo felt confident letting нім staff "enter in [his] intimate zone" without "feeling intimidated or ashamed." For many men, participation in this research program that was in, but not of, the IMSS gave them access to the care they felt they were owed by the state in a more timely and reliable way. They were so pleased with the attentive care and range of tests that they often characterized their visits as providing a thorough checkup, despite the testing's actual focus on sexual health issues.

## THE HIM STUDY AND POPULATION

The HIM study is a multinational investigation of the "natural history" of HPV in men. Human papillomavirus is actually a family of viruses; some can cause warts and others can cause pre-cancerous or cancerous lesions, which can affect many areas of the body. Genital HPV strains are collectively considered the world's most common sexually transmitted infection (STI). While most people who contract HPV never experience symptoms

(although they can transmit the virus while it is active), some infections lead to genital warts or cancers of the cervix, penis, anus, head, and neck (Clifford et al. 2005). Since cervical cancer is by far the most common HPV-related cancer, and since women's sexual and reproductive health is under far more scrutiny than men's, HPV is often seen as a women's concern. The HIM study aims to shed light on men's epidemiological experience of HPV, since men are as likely to contract and transmit it as women, but little is known about this phenomenon.

The HIM study is funded by the U.S. National Institutes of Health but has an international scope, with sites in the United States, Brazil, and Mexico. The study aimed to establish a group of three thousand men who would be tested for HPV every six months for four years to shed light on how the virus develops and clears in men and better understand the health and behavioral factors that lead some infections to clear and others to persist or become symptomatic (Giuliano et al. 2006). Enrollment began in 2005, and testing continued long afterward as the study found additional grant support. The study was a longitudinal and observational study, which means that it monitored participants' biological changes over a long time span rather than testing a health intervention. This makes it a different setting from the shorter-term, intervention-based clinical trials on which much social-science research has focused. Because of its long-term influence on participants' daily lives, and the reflection on their behavior and biological changes that it can generate, longitudinal, observational research is an ideal setting for investigating how people incorporate medical research participation into their broader, ongoing efforts to be particular kinds of people and cope with specific social changes.

Participants in the HIM study were tested with new DNA technology that reveals previously undetectable asymptomatic HPV infection. At each visit, participants also completed computerized surveys regarding their health and sexual practices and received written records of their prior STI test results. At the Cuernavaca site, participants did a circuit of tests, moving among the various stations set up in the research clinic. They gave a urine sample in the bathroom, had blood drawn at the phlebotomy station, sat at the computer carrel to complete the questionnaires, then entered a private cubicle with the physician's desk and an exam bed for their HPV testing.

Given the length of the study, participants and staff got to know one another well over time; the staff also prided themselves on being friendly and open to encourage participants to keep returning. As participants moved through the tests, they would chat with staff about their families and children, providing life updates about the previous six months. The two physicians,



one male and one female, who did the genital testing also had cordial relationships with the participants. They would catch up, although, as the female physician noted, "total silence" fell once men sat on the exam table. For genital testing, men were asked to strip below the waist and lie on a bed. The doctor would observe the men's genitals for signs of sexually transmitted infection, then rub cotton swabs along their penis and scrotum (as well as their anus for those men who consented). If necessary, they would also offer STI-related medical treatment, such as the removal of genital warts. After the genital exam, the participant (and his wife, if she had accompanied him) would sit in an office with the physician or clinical director to receive an explanation of the STI testing results from the participant's last visit. Men were given a slip of paper that stated whether they were negative or positive for "low-risk" (potentially wart-causing) or "high-risk" (potentially cancercausing) HPV strains. The staff member would explain the possible consequences of the diagnosis, suggest that wives of high-risk positive men be screened for cervical cancer, and answer questions.

The study was run by a Cuernavaca-based public health research unit of the IMSS. Thus, it was based in the IMSS offices—first, in the regional IMSS hospital, then across the street, and finally in the purpose-built research clinic in the city center that had been under construction since the inception of my research. These sites were sunny and clean and decorated with research posters from the unit's other projects, which connoted a privileged position in the IMSS hierarchy and framed the office as a site of successful knowledge generation. These IMSS connections were crucial to study recruitment. The study recruited heavily within the IMSS staff and patient populations, as well as at local universities and large businesses with IMSSeligible staff (Giuliano et al. 2006). It is illegal to pay medical research participants in Mexico, so Mexican HIM participants were uncompensated aside from free STI treatment and a few courtesy medical tests (including cholesterol and bone density testing) offered to them and their spouses. Thus, recruitment focused on the individual and societal benefits of participation. The HIM staff gave talks discussing HPV, related cancers, and the fact that men can have and transmit the virus. They called on men to aid in the research endeavor and noted that the HIM study was the only way for men to get HPV testing. Many participants recounted that their own or their wives' attendance at one of these talks was their impetus for joining the study.

The staff also used posters, placed throughout IMSS clinical buildings, to recruit men by framing participation as a way to support others and perform modern and responsible masculinity and fatherhood. For instance,

one poster combined images of men, boys, and infants to call on men as fathers to aid in prevention efforts. Another showed the respectable and proud-looking male HIM staff members, together with an image of men's raised fists, with the wording "Together for Men's Health"; the heading "You Can Help by Participating in This Important Study" was superimposed over the backdrop of the IMSS regional hospital. This sent the message that men could enact companionate responsibility while supporting and benefiting from government care.

This kind of framing appealed to a specific group of men who tended already to be working to support public health and seeking to live out what they saw as modern masculinities. Overall, while formal HIM inclusion criteria focused on the absence of an active STI, the Cuernavaca HIM population also had a higher level of formally employed, highly educated, and relatively economically stable participants with access to state health care than the population at large. The reason was that participants recruited at the IMSS and private companies were usually formally employed, a status that provides relative economic stability (though not necessarily wealth) in a country where most people work in the informal economy (INEGI 2009). Many participants and their spouses were state workers, mostly in the IMSS, but also in education and scientific research.

The subset of this group who participated in my research were likely especially predisposed to relate medical research participation to broader life projects, including those involving the sorts of care on which many focused professionally in state health and education jobs. As I discuss further in the appendix, HIM staff recruited for my study and selected participants they thought would be willing to participate. This meant inviting those who seemed especially invested in HIM participation, had demonstrated an interest and willingness in talking about their broader lives and the HIM study's place within it in informal conversations during medical procedures, and reliably showed up to appointments. It was fairly common for participants in my study to say that they were interested in doing our interviews because they believed in the merit of research generally, wished to support the IMSS and IMSS-allied initiatives that could help others, and found meaning in talking about their life experiences. This population was thus a subset of a subset. They were probably not representative of all Cuernavaca HIM participants, some of whom might have enrolled with primarily medical benefits or other ends in mind, or might have experienced HIM as a clinically bounded or generally unimportant experience. Their specific experiences are important to understand not because they are representative, but because



they reveal how people can use medical research participation to further context-specific, extraclinical ends unanticipated by study designers.

For the anthropological study population, these contexts included the discourses on Mexicanness and gender and the experiences of the economic and violence crises, discussed earlier; they also included a specifically urban, middle-class take on long-standing local cultural ideologies regarding collectivity. People across demographics in Mexico often cite emphasis on familial closeness as both a fact of Mexican society and a matter of national pride (cf. Crowley-Matoka 2016). This emphasis is not limited to kin. For example, casting Mexican society as one "revolutionary family" served as a postrevolutionary political justification for single-party rule (Zolov 1999). Deliberately creating and expanding one's kinship networks has also been a feature of Mexican society since conquest. The system of compradrazgo—a form of ritual kinship in which parents select people to be their children's godparents, and thus their own coparents, as children go through Catholic life-course rituals has served to create relationships of mutual aid and obligation (Carlos 1973).

While cultural emphasis on the family endures, what kinship looks like amid urbanization and cultural efforts at "modernization" has changed. For instance, forms of compradrazgo had already shifted in cities by the 1970s, with the creation of ties limited to only baptism rituals and more likely to be made with existing kin and people from one's socioeconomic stratum than powerful patrons (Carlos 1973). The rise of Mexican versions of globally emerging "middle-class" subjectivities also involved shifting conceptions of family. In Mexico, the emergence of this sort of middle class occurred amid both economic crisis and partial government efforts toward neoliberal governance and the related logic of capitalist individuality. Thus, middle-class subjectivities came to involve emphasis on personal development that could contribute to familial, rather than primarily individual, well-being in an uncertain world (Careaga Valdez 1987; Vieyra Bahena 2018). This process, in tandem with the idealization of companionate marriage and its emphasis on the marital dyad, led to a change in focus within the meaning of family for middle-class Mexicans, from a focus on extended kin networks to nuclear families (Ramirez and Everett 2018).

The HIM participants I interviewed overwhelmingly emphasized the importance of family in these terms, merging characteristically middle-class aspirations for personal development into efforts to enhance collective wellbeing, significantly, but not only, at the level of the family. This emphasis on leading others forward through self-care and development notably displaced emphases on mutual aid through systems such as compradrazgo. Although

such ties remain key to social life in many Mexican contexts (see, e.g., Cant 2018), participants in my study never mentioned them at all.

Middle-class takes on family were also evident in relationship to participants' conceptions of health. The main contribution of this book is to highlight how people hoped men's participation in the нім study would aid the biological, as well as social, well-being of others with whom they were related. Yet they focused these hopes on experiences with biomedicine, a healing system focused on individual patients. Valeria Napolitano (2002) argues that, in the pluralistic healing worlds of urban Mexico, people's choices of health intervention also reveal their ideas about how forms of sociality influence sickness. She notes that by choosing particular modalities, such as traditional Chinese medicine, people simultaneously cope with the local economic and other constraints on health-care access while aligning themselves with particular visions of modernity or cosmopolitanism (Napolitano and Mora Flores 2003). In this light, it is notable that HIM participants avoided the traditional healing practices that remain common in Mexico, even though these practices resonate with collective visions of health. Such practices often focus on relationships in ways that range from healing the physical consequences of relationships gone awry (in the case of witchcraft beliefs) and cleansing the energy of the homes and family of sick people (as sometimes occurs in the more mainstream versions of curanderismo commonly practiced). Aside from one participant who received a certification to teach traditional Mexican healing in a university setting, participants who used complementary forms of healing focused on imported systems that had a more elite cultural cachet. Some used traditional Chinese medicine, and several took and sold supplements such as Herbalife that fused scientific-sounding promises with logics of capitalist self-improvement. By reframing biomedicine as a health intervention that could act on relational problems, participants crafted distinctly middle-class takes on collectivity that fused culturally resonant emphases on family and relationality with the use of systems that signaled modernity and upward mobility. (For other examples of the emphasis on family relationships as central to patient care within Mexican biomedicine, see Crowley-Matoka 2016; Hale 2017.)

## The Study Design

This book is based on a series of annual interviews with thirty-one heterosexual HIM participants and their female partners, comparison groups of ten men and twelve women interviewed without their spouses, and HIM staff.



In the appendix I discuss the study design and how I analyzed data. Briefly, I did the open-ended Spanish-language interviews from 2010 to 2013, with additional follow-up in 2015. My goal in focusing on couples rather than individuals was to center collective experience from the start to understand sexual health as an interpersonal rather than individual experience and to more easily identify the consequences of men's participation in medical research over time beyond their individual bodies. I focused specifically on heterosexual couples both because the vast majority of Mexican HIM participants had female primary partners and to understand how changing ideologies of heterosexual marriage had influenced couples' study experiences. I did not find significant thematic differences between the statements of couples interviewed together and individuals alone, with the exception of some people's willingness to tell me marital "secrets" individually that they did not wish to share in front of their spouses.

Focusing on interviews was the best way to study relationships between HIM participation and peoples' daily lives, given the particular constraints of a medical research study field site. Cultural anthropologists famously use participant observation in people's daily lives to gather diverse forms of data regarding what people do, which is rarely identical to what they say or think they do. Yet medical research studies—and anthropological studies of them—are required to guarantee participant confidentiality. This meant that I had to confine my research with HIM participants largely to the clinical setting. I was permitted to interact outside the нім offices only with those participants who chose to invite me to do so; I could not ask for such invitations, as this might pressure participants to compromise confidentiality. Most who did so were evangelical Christians, so data from participant observation appears largely in chapter 6, where I discuss that group's experiences. In most participants' cases, interviews were the most feasible and appropriate method for me to understand how spouses collaborated to make sense of the interactions between their HIM and broader life experiences.

Both my conduct and analysis of these interviews were shaped by an "ethnographic sensibility," which the anthropologist Carole McGranahan (2018: 4) describes as a culturally rooted "commitment to interpersonal relations as the base of knowledge" reliant on insights from a researcher's long-term engagement with people and place. The interviews were designed to address topics I suspected from experience would be relevant for participants' understandings of HIM involvement and to enable participants to raise issues I had not anticipated. My goal in structuring the interviews was to encourage

participants to guide the conversation to their own topics of interest, and for couples to talk together, so that I could learn about their interactive efforts to make meaning out of medical research experience in this particular social setting. As they did so, I paid attention to their nonverbal interactions and silences, as well as their narratives. I understand the resulting data to reveal peoples' joint and sometimes interpersonally fraught efforts to be particular kinds of people in research-related settings. Since people are likely to be strategically vague about potentially stigmatizing sexual issues in daily life but more open about them in medical settings (Carillo 2002; Finkler 1991), these interviews provided a unique space for such efforts.

I analyze the content of these interviews not as a journalistic reflection of experience, but as context-specific presentations of self that people created in collaboration with all those present (Jackson 1998; Linde 1993). This includes myself. The fact that I am a woman likely facilitated men's discussion of vulnerabilities and women's discussions of their experiences, but it also probably precluded specific presentations of self such as more "traditional" masculinities (González-López 2005; Hirsch 2003; Hirsch et al. 2007). My U.S. nationality likely encouraged participants to speak of themselves "as Mexicans" and seek to educate me on what they thought that meant. Participants expressed strong and contradictory views of the United States, describing it as simultaneously aspirationally modern and wealthy and a driver of racialized economic inequality in the region. They understood me, as a white American, as representing both of these aspects. Thus, I became an audience for critiques of U.S. culture and dominance, as well as an interlocutor understood as sympathetic to modernizing projects, including those with implicit goals of population whitening. My status as a researcher amplified the latter feelings of kinship, with participants in medical and academic careers understanding me to be from a similar work milieu and to hold shared goals for aiding society through our labor.

Any research methodology opens a window onto the issue under study, revealing that which is visible from a particular angle and vantage point (Haraway 1988). In this study, interviews revealed people's context-specific reflections about physical and social interactions, as well as spouses' collaborative efforts to make narrative sense of them. While inherently partial, the view presented here reveals key and little-known ways that people can incorporate ostensibly individual medical research participation into efforts to affect their and others' lives and bodies beyond the clinic.

[32] CHAPTER ONE RSITY
PRESS

## Aims of This Book

In the chapters that follow, I show how HIM participants and their partners incorporated the medical research experience into efforts to care for social bodies and heal the collective biologies to which they belonged. I analyze their narratives of research participation to reveal how they hoped this activity would be useful at multiple levels of scale.

Chapter 2 initiates the analysis of HIM participants' experiences at multiple levels of scale by exploring men's personal experiences of gendered selfhood and change. I discuss men's efforts to incorporate medical research involvement into performances of companionate responsibility, done in collaboration with their wives and in relationship to enduring ideologies of machismo. The chapter thus shows the "individual" level of gendered selfhood to be fundamentally relational, in context-specific ways. In chapter 3 I explore how the gender ideology participants articulated in chapter 2 influences their understandings of HPV biology, transmission, and the social risks it could pose. I show that spouses drew on local ideologies of collective biology to frame men's individual HPV testing as a way to monitor and enhance the health of their shared "couples biology." In chapter 4 I discuss how couples' HIM participation reflected and enhanced their ability to be good parents—for example, by ensuring they would be healthy enough to support their children and enabling them to model health-promoting gender and marital practices for them. In chapter 5 I investigate how participants and partners also hoped to advance the Mexican social body as a whole through such modeling. This analysis shows how they sought to advance the nation by embodying and promoting a "culture of prevention" related to non-macho masculinities and companionate marriage. In this way, HIM participation came to serve as a form of citizenship though which couples supported the spirit of national public health programs and strove to guide the Mexican populace forward, despite rising violence and the unreliability of their slippery state. Chapter 6 focuses on evangelical Christian participants' experiences. I discuss their incorporation of the HIM study into pious efforts to embody and model the health, gender, and marital practices their churches promoted. This adds complexity to the prior chapters' analysis of participants' use of a local ideology of collective biology to understand HIM participation by demonstrating how people draw on multiple ways of understanding the world to make sense of such pursuits. In chapter 7, I conclude the book by discussing the utility of the collective biologies approach for investigating relationships between individual behavior and the well-being

of broader, nonindividual bodies. I suggest ways that this approach can be used in medical research, its ethics oversight, and public health practice.

Through this inquiry I show that seemingly individual health behavior can have embodied social consequences that extend widely beyond the clinic and the individual body. My findings broaden our understanding of this phenomenon in medical research, since social-science study of that field has focused on resource-poor or marginalized participants seeking care or social inclusion through short-term global clinical trials that test medical interventions (see, e.g., Elliott and Abadie 2008; Geissler 2015; Nguyen 2009; Petryna 2009). These findings also shed light on the understudied role that gender plays in people's medical research experiences.

Beyond the case of medical research, the present study reveals how middle-class people incorporate long-term health surveillance into ongoing daily life efforts to be good and modern people, partners, parents, and citizens. The findings discussed here are specific to the Mexican context, where mestizos have long been encouraged to view their health practices as ways to set themselves apart from Indigenous or impoverished others. They are also influenced by the violence crisis that struck Cuernavaca during the study, to which they responded by framing HIM participation as a way to help others and contribute to national health and modernization at a time of instability. Yet I use these specific insights to make a broader point: that attending to multiple levels of scale when assessing medical research participation, health surveillance, or, indeed, any health behavior is necessary for understanding how people draw on local cultural currents and events to assess the embodied consequences of their actions.

I hope that the analysis in the coming chapters can model a way of identifying and assessing the complexly biosocial interrelationships between individual behavior and the well-being of the particular nonindividual bodies that exist in specific cultural settings. I offer the analytic of collective biologies as a way to operationalize this study of relationships among bodies on multiple levels of scale. This book is a study of how people can collaborate to use seemingly individual health practices to treat collective ills. In it, I aim to model an approach that could also be useful for understanding this phenomenon in diverse cultural contexts, and beyond social-science inquiry in medical research design, ethics oversight, and public health practice. I also hope this analysis will model a way of assessing how people can draw on collective ideologies in responses to pressing problems, despite globally increasing political and economic pressures toward individualization.