Preface

We wrote this book for scholars and researchers who are ethically motivated and who want their truth seeking to improve the world. We hope this book will accompany you and offer support as you develop your ethical attunement to the complexities you will face in your work.

Our book illuminates ethical matters largely left in the dark by contemporary research ethics guidance, including biomedical, legalistic, and/or procedural models underlying federal law, institutional review board (IRB) or research ethics board (REB) guidelines, current professional codes of ethics, or standard textbooks or textbook chapters on these topics. Our hope is that our relational and reflexive approach to an ethical praxis provides a firmer foundation for engaging the ethics of research for all scholars, particularly those engaged in community-based and participatory approaches to research.

While we believe that formalized research ethics processes have utility by calling attention to some key principles for guiding action and asking researchers to be self-reflexive and accountable, we offer a more expansive perspective on these principles that alters some of the assumptions and narratives of codified ethics. Our approach thus aims to be both a counterpoint and a complement to the kind of research ethics training that procedural research ethics have typically produced. Support for ethical reflection and deliberation is especially needed in a context where a wider range of research projects are considered exempt or expedited in formal review since the revision to the Common Rule in the United States in 2018.

While much scholarly attention has been devoted to examining the principles, procedures, and development of IRB/REBs, including their limitations, there has been limited pedagogical guidance to help scholars enact ethical research, and even less guidance for an ethical praxis informed by critical theoretical and collaborative methodological frameworks. Even though doctoral programs commit time and study to the complexities of epistemic matters, they often neglect ethical complexities and the intersections of ethics with knowledge production and research practices. Many doctoral programs do not sufficiently support the knowledge, skill, and disposition development needed to navigate complex ethical matters. We hope our book fills that gap and provides a companion for those of you embarking on, or traveling further along, your own journey of becoming an ethical researcher.

Our book argues for a praxis of ethical engagement that is relational and ongoing rather than procedural and episodic. This means that ethical life and ethical scholarship are journeys more than destinations. We offer this book as a companion for that journey. Our praxis pauses, ethics stories, and question sets are meant to be prompts to ever deepening understanding, ever more ethically attuned scholarship. We will ask you to reflect on and activate your own experiences and perspectives in dialogue with your collaborators.

Our pedagogical and reflexive materials do not provide settled answers to the knotty ethical challenges that you may face. Instead, we hope to open pathways for deeply considering and engaging with these enduring, complex issues. We offer our frameworks not as road maps to an ethical purity of some sort, nor to assure goodness or provide immunity from conflict in research partnerships. We understand the praxis of an ethical life to mean simply a willingness to grapple honestly with the always fraught and enduring ambiguities, contradictions, and imperfect choices that confront us.

We hope our book will support you to develop an ethical praxis that is relevant and responsive to the conditions you work within. We emphasize the importance of finding your way through ethical deliberation not in isolation but actively accompanied by a community of practice. This community may include people who are similarly committed to making ethics central to their scholarly life and who will hold space for feedback that is loving and critically accountable. This is central; as reading this book will demonstrate, we believe that ethical matters are intertwined with epistemic, relational, and contextual considerations and cannot be fully attended to as an independent endeavor. In this way, our book is meant for communities of readers who want to discuss complex and difficult ethical matters in order to strengthen their scholarship and increase its impact.

We explore generative questions pertaining to the ethics of research for scholars in any discipline or interdisciplinary field. However, people in the social science and humanistic disciplines and various critical interdisciplinary fields and people engaged in collaborative, participatory, and community-based research will find our examples and pedagogical materials most directly relevant. In addition, we hope this book will fill a gap for scholars outside these broad disciplines but who likewise seek to engage in research that matters in communities. We imagine an audience of readers primarily of graduate students, and we also imagine dialogical circles of students and faculty, colleagues and collaborators, who read and engage with our pedagogical materials together. We hope our book provides guidance and sustenance for your journey(s).

Our Journey(s)

Our book itself emanates from an interweaving of individual and collaborative journeys, from a juxtaposition of life and institutional histories, that made possible our multiyear, multilayered investigation of the ethics of research. We met through the Center for Collaborative Research for an Equitable California (CCREC) while serving as director (Ron), postdoctoral scholar (Natalie), and graduate research assistant (Sheeva). From 2009 to 2015, CCREC was a multicampus research initiative that linked interdisciplinary university researchers, community organizations, and policymakers in equity-oriented, collaborative, community-based research projects. These projects addressed intersectoral challenges in the economy, education, employment, environment, and public health. CCREC was created in an effort to build institutional capacity for collaborative, community-based research methodologies within the University of California (UC) system,

and it prepared a new generation of engaged scholars and community leaders who seek to make truth matter in the public sphere.

The interdisciplinary ethics team at CCREC was supported by two major grants from the Spencer Foundation, leading to a rigorous testing of our frameworks in our invitational *Unsettling Research Ethics* conference (Baloy et al., 2016), a variety of inter/national conference presentations and workshops, and numerous published studies with CCREC team members and collaborators. The framework and pedagogical resources we elaborate in this book were built from our iterative analysis and coding of approximately 55 ethnographic interviews with scholars conducting equity-oriented collaborative research and with community-based research partners. We also undertook critical reviews of research ethics laws and regulations, research publications, and professional and Indigenous research ethics codes. Our ethics stories are fictional composites that weave together the voices of our interview respondents along with voices from the literature, our own experiences as community-engaged researchers, and current and historical contexts that shape research.

The "we" in this book is interdisciplinary, jointly authored by a critical philosopher of education (Ron), a critical feminist anticolonial anthropologist (Natalie), and a critical race and anticolonial feminist foundations of education scholar (Sheeva). Everything in this book is truly the product of our collective voice and writing, and we share first authorship to reflect this.

Sidebar 1

Situating Ourselves

This book is also the story of ourselves as people who, like you and those you collaborate with, are navigating the complexities of life—from deaths, separations, moves, new jobs, births, and more. We ourselves had to pause our collaboration in 2018 due to some of these experiences in our lives, and soon after, the broader social context also became marked by upheavals: a global health pandemic; the racial reckoning of 2020 and the ongoing white backlash to it; the deepening symptoms of the colonial climate crisis, including heat waves, fires, and more. Each of us bears witness to our own unfolding histories and the past, present, and futures of the social worlds we inhabit.

Ron: I come to the ethics of research through my familial and communal ethical principles, my philosophical pursuits, and my social and political commitments. My grasp of ethics as an embodied praxis emerged from studies in neurology that began at home in my early teens and later in my university studies in the history and philosophy of science, in phenomenology, and in critical theory. My perspectives about ethics also emerged from my

engagement in the 1960s struggles for racial justice and an end to the Vietnam War, my confrontations with the elite universities I attended over their involvement in militarism, and my ongoing efforts to build communities that were/are committed to living otherwise. In all these life experiences, these studies and projects, I try to face the ways in which I am implicated in the "isms" that my communities and I seek to overcome and to understand how my own life is fraught with contradictions and ethical missteps. I remind myself that the bulk of my income in "retirement" still comes from the University of California, the institution that designed the first and only nuclear weapons ever used in warfare and that has continued to design every subsequent generation of these weapons of mass destruction for the U.S. military, a reminder that keeps me ethically humble and resolutely committed to enact what justice I can. And as a son and brother, father of three, and grandfather of seven, I have learned most about truth and ethics in response to these amazing people who have loved me.

Natalie: When I reflect on my moral formation, I think of the dinner table at my Grandma and Grandpa Keiser's house, the church basement and fellowship dinners at the Lutheran church where I grew up in small-town Ohio, the garage of my aunt's house where my mom and her sisters took breaks from cooking, my Aunt Julie's house where my family gathered with friend-families to celebrate or grieve, walks around the playground at elementary school with my best friend Ashley, and the back room of Barnes and Noble where my coworkers and I talked about politics, philosophy, love, and stories. I think of the transformative experience of learning in and from community in Gitxaała, or hearing Musqueam elder Larry Grant remind listeners at University of British Columbia events that we were on Musqueam land, or walking in the streets after the murders of Michael Brown and George Floyd, or witnessing my friends as we navigate our lives and work and try to live in good relation to each other, our communities, and the lands and waters and beings around us. I think of my training as a white settler ethnographer and cultural anthropologist in a department and among graduate cohort members confronting colonialism and white supremacy and patriarchy, of my collaborations in research and in life. Through watching interactions between family and community members, listening or talking with my loved ones and friends, reading novels and critical theory, creating curriculum with colleagues and students, being a daughter and a sister and now a mother, and being alive in a sometimes bewildering and often unjust world, I have tried to find my way alongside my beloveds and collaborators through ethical tensions amidst injustice and toward a relational, ongoing, and imperfect ethical

praxis, as a scholar and as a person committed to bringing more just futures into being.

Sheeva: My moral formation began in spaces created through love, community, and longing. My parents immigrated from Iran, refugees of religious persecution. I attended small Sunday school classes run by parents and community members where we studied virtues, learned about principles such as the equality of all peoples, and recited prayers. I also attended schools in predominantly white, middle-class suburbs; my family's access to educational privilege and slowly rising economic security contributed to a stable childhood. Still, I picked up on the subtle messages that we were outsiders. I yearned for what had been lost, for connection to place, for belonging, and didn't have words to name these tensions. In their relief that our family was safe from state-sponsored violence, my parents didn't discuss the traumas they had endured, nor how they had to go above and beyond, working tirelessly to prove themselves as immigrants. Love remained the constant current of home; it informed my sense of social justice. During my undergraduate studies, I was exposed to histories to begin unpacking my family's experience with criticality, to go beyond dominant narratives upheld in schooling. Seeking alignment with that inner, ethical compass seeded by family and community, I found spaces rooted in critical study and collective liberation when I returned to graduate school. My ethical formation continues to be nurtured by loved ones committed to this lifework, like Ron and Natalie. As an educator, I see the connections between the movement-rooted ways of knowing and collective change-making that guide my work with the values I learned at home.

Our Journey With You

We do not enter into community-engaged research solely as "researchers," "community partners," or any other role but as whole, complex people whose identities are shaped by history, the present, systems of power, institutions, our communities, families, social networks, and ourselves and each other. Likewise, the communities we live and/or work in have their own histories and relationships to institutions and are composed of people with their own complex personhoods, all of which inevitably informs the very issues that research for justice hopes to intervene in and address.

The analyses we offer are not entirely philosophical in the sense of engaging primarily with philosophical literature about ethics; similarly, the ethics stories we offer are not entirely empirical in the typical social science sense. We draw from a variety of critical

genealogies to situate ethics, contextualize the reach and limits of IRB/REB framings, and offer ways forward to better cope with the interactions among epistemology, ethics, and power, including within the racialized and colonial violence that can be created and extended in and through research.

More scholars in recent decades have called for support within academia for community-engaged research, in part to address ethical concerns with extractive forms of research and with findings that are interpreted to frame communities within deficit ideologies (for example, see Tuck 2009). But even as community-engaged approaches to research try to keep a focus on ethico-epistemic intersections, there are always remaining, persistent, enduring ethical tensions and questions that arise, some specific to collaborative and community-based modes of inquiry (Glass et al., 2018); this book helps prepare scholars to anticipate and address them.

We recast research ethics in a wider view of the ethics of research and emphasize ethics of research as a praxis rather than mere procedures. Through our distinctive critical perspective and pedagogical features, we hope to accompany readers and communities of scholars in their work and to contribute to the transformation of existing professional communities of practice to bring ethical issues to the forefront of scholarly work. We hope that you, our reader, help in these transformations of our professional spheres through your own collaborations.

Whether you are just beginning a course of study to become a researcher or are an experienced scholar now reflecting more systematically on ethical issues in your discipline or methodologies, we hope our book offers you a helpful companion in your work. We also designed our pedagogical tools to be accessible and relevant to readers working in community organizations, schools, or government agencies, and collaborating with university researchers or conducting your own research to impact policies and improve community life. We hope you find support and guidance in these pages and in reflections and conversations generated by these materials.

We hope this book will reach you wherever you are on your journey, that it can enlighten and enliven your research and collaborations. We hope our readers bring us into conversation with their own work and with their partners in that work. We are honored that this piece of our life's work is now in your hands. Welcome, and thank you for joining us on this journey.

Chapter 1

Research for Justice

What is the purpose of research? What role does research play in making social change—and what kinds of change? Is research always a good thing? Good for whom? In what ways? What are the intentions and impacts of research on humans, non-human beings, and the social and material world? How do social, economic, and political conditions shape research and vice versa? Where and when does research happen? By whom and for whom?

In this chapter, we explore these and related questions to excavate some common assumptions about research and to examine the role of universities as primary sites of research. We also emphasize key interventions from critical scholars who highlight how research and research institutions can reflect and reify inequitable systems of power. We introduce community-engaged research for justice as a suite of interventions from scholars and community leaders who aim to address power dynamics in research through collaboration, co-creation, and action; yet here too we emphasize enduring ethical matters that demand attention.

What Does It Mean to Do Research?

Pause for a moment and think about what you actually *do* when you "do research."

At its most basic level, research involves everyday practices such as asking questions and defining terms, observing and documenting what's going on around us, experimenting or trying things out to solve problems, reading to acquire new information, or discussing and critically analyzing experience with colleagues and friends. Perhaps you inquire or investigate to know better what you already know, to address social problems, or to open up new domains of understanding of what was previously unknown or only hinted at. You may also bring people together to do these things, with different areas of academic or grassroots expertise and different knowledge bases adding to the analysis to address a real-life issue.

To do research like this, scholars follow some systematic methodology to gather evidence and make arguments to produce knowledge that is recognized and circulated within some community(ies) of practice (Lave & Wenger, 1991; Wegner & Wenger-Trayner, 2015), including those that comprise the academic disciplines or that formulate and enact policies and laws.

Your own implementation of community-approved methods and analysis of data will help warrant the claims you make. Your community(ies) of practice may offer critiques and suggestions for improving your methods, interpretations, and arguments. For those of us who work in universities, the process of "peer-review" is one way that communities of practice (our peers and fellow scholars) review the execution of research. For community-engaged scholars, this community of peers should include community leaders who partner with researchers.

Within particular paradigms or disciplinary frameworks, only specific methods, types of measurements and documentation, and forms of arguments are considered acceptable to justify or warrant a knowledge claim; these methodologies also set the scope for what is even "knowable" at all. Thus, we might think about how the ability to make a knowledge claim that is recognized as legitimate also carries certain forms of power: power to describe or name reality, to diagnose problems, to prescribe solutions, or to validate particular beliefs as truths. Community-engaged scholars enlarge the circle of legitimated knowledge holders who can contribute to knowledge production.

Epistemology, or the theory of knowledge, refers to how we understand the difference between justified belief and mere opinion. Epistemology not only invokes theory but also processes for collecting evidence and criteria for analyzing its significance in order to make various types of claims about disparate realms of experience. Different communities of practice may have dissimilar epistemologies, or ways of discerning the lines between warranted truth and mere belief, lines that differentiate patterns from anecdote and chance, lines that mark the boundaries of the knowable and unknowable.

Community-engaged scholars in the social sciences and humanities, and in the variety of critical interdisciplinary fields, necessarily must grapple with a diverse epistemic landscape; this grappling with epistemic diversity itself is imbued with ethicality. How does one move with respect in such a landscape, attentive to the reach and limits of epistemic positions and claims? And as we will elaborate in a later section, similar grappling must occur in relation to moral diversity.

How Do Universities and Academic Disciplines Shape Research?

As many scholars have argued, the university system in the United States emerged through and alongside settler state formation, the rise of racial–global capitalism, and a hierarchical relational order that places humans above nature (Boggs & Mitchell, 2018; Stein, 2022; Wilder, 2013). With these orders also came the establishment of the epistemological system of "Western universalism" that asserted as true and right the hierarchies of certain people (white, protestant/Christian, cis-hetero-male, upper-class, able-bodied, etc.) above peoples deemed to be "others" (racialized, Indigenous, non-Christian, women, LGBTQIA+, poor, disabled, etc.). The claimed universal epistemic and moral orders aligned to justify and maintain social systems of power. Because of how U.S. higher

education is imbricated in this history, anticolonial, antiracist, and abolitionist scholars question common narratives about colleges and universities as spaces that promise and produce continuous progress, benevolent public good, and social mobility. Troubling the dominant narrative about universities and their knowledge production and legitimation systems means to recognize how they have been and continue to be entangled in interlocking systems that normalize and reproduce oppression (Boggs & Mitchell, 2018; Ferguson, 2012; la paperson, 2017; Patel, 2021; Sabati, 2019).

This broader historical and structural context is reinscribed in more subtle ways in the everyday practices and workings of universities and in the logics of reproduction of the professoriate. Questions of power and value are at play in the metrics of what sort of research is most valorized or rewarded within particular disciplines; for example, in some fields, the valorization of the solo-authored publication in a top-tier journal might deincentivize new faculty from community-engaged research and shared authorship. While there has been work across disciplines, institutions, and journals to expand definitions of "rigorous" scholarship (Balazs & Morello-Frosch, 2013; Eatman et al., 2018; Warren et al., 2018), there remain ongoing contestations over the value and strength of community-rooted research (Serrano et al., 2022).

Similar questions at the intersection of epistemology and power shape public and private grant funding opportunities. The U.S. federal government's 2025 defunding, freezing, and curtailing of research grants that focus on marginalized communities or that seek to address equity and inclusion speak clearly to how questions of power are always at play in the formulation of research. While research and knowledge production are not dependent on nor solely bound by universities as well as public and private grants, there can be no question that these institutional forces empower the claims of the types of research that they sponsor and legitimize.

We, too, emphasize that institutions of higher education are intertwined with structures of power, past and present, including settler colonialism, anti-Blackness, and class division; this history and its contemporary expression must be addressed from a moral point of view in teaching and research. Universities serve as foundational social institutions and imbue the academic disciplines with structural power as specific traditions that shape the rules of epistemology, or what comes to count as knowledge. At the same time, the role of universities, and the reach and limits of the knowledge that universities generate through research, are contested, as are the relationships between university-generated research and social, economic, and political life.

Power is thus embedded within academic research and knowledge production, with real ethical and material implications for how knowledges re/construct our social world and relations. This is especially true when policymakers draw on research. That is, while "evidence-based" policy is generally understood as a desirable objective, the framing of research questions, theories used, types of evidence gathered, and their interpretation, all inform what kinds of "evidence-based" policy are created. For example, in the United States and globally, Keynesian economics and neoliberalism have been used to rationalize policies that concentrate wealth accumulation amongst the elite,

erode living wages and dignified labor conditions for workers, while also limiting the political imagination of many to be constrained within these same economic frameworks (Spence, 2015). Traditional Western and disciplinary epistemologies assume a hierarchical and separatist structure of relations in which the production of knowledge resides primarily with a researcher outside the phenomenon under study. Not all knowledge traditions function this way, even within the university (e.g., anthropology), and some Indigenous epistemologies and collaborative research methodologies also challenge this form of knowledge production. Tahana Athabascan scholar Dian Million writes, "It is my position that all epistemologies are open systems reflexively formed in the same cauldron of living story, conjecture, place writ large, and practice that produce our own conceptual maps. Any difference stems from the uses that these modes of knowing are put to" (2015, p. 339).

Collaborative research situates the researchers and traditional research "subjects" as coequal and coresponsible partners who work closely together in the research process from start to finish as its ideal form. In this way, knowledge production is understood theoretically and enacted practically as a collective and collaborative process. Valuing knowledge that emerges from peoples' lived experiences and the specificity of their contexts can help to warrant the knowledge that is produced. Just as importantly, this situatedness of knowledge contributes to the meaning and value of the knowledge for those very peoples and places.

Thus, those historically excluded from the design, implementation, and interpretation of the research (the prototypical "research subject" when investigating "social problems") instead come to play an intentionally integrated role in the research process. For engaged researchers and partners, working together collaboratively with/in communities seeking redress from injustice begins to provide a structure or practice that acknowledges the intertwining of the ethical and the epistemological in all research endeavors.

Can Research Be Neutral?

Since the late 19th century, U.S. universities have generally been explicitly committed to what is termed "disinterested" scholarship and "neutrality" in the public sphere. These values have been prioritized to warrant certain qualities of research: that it is untainted by conflicts of interest or personal bias on the part of the researcher and that it relies on reviewable facts to undergird objective analyses that have no political allegiance. The commitment to these values is meant to fortify and defend academic freedom within the scholarly community and in the larger community, as a defense of the academy itself from external interference, particularly from the state or religious authority.

We agree that research and scholarship require a bulwark of defense in the public sphere to prevent governmental, religious, or corporate power from dictating research questions, methodologies, analyses, and interpretations. We also agree that issues of conflict of interest and researcher bias are of concern, although we see these issues in a wider

scope than is typical, one that calls all researchers into deeper grappling with ideological biases, and with institutional conflicts of interest as well as personal ones.

All modes of inquiry express perspectives, including those that claim a disinterested or neutral perspective. Research conducted in purportedly objective or neutral ways can materially maintain an unjust status quo within economic, political, and cultural institutions and arrangements, which is not a neutral outcome. Research has long been produced and cited to justify stratifications of wealth and power and to rationalize, reinforce, and reproduce unjust social hierarchies based on language, race, gender, and other reified and taken-for-granted human characteristics. To counter this history, collaborative and community-based research toward justice and social transformation takes a principled stance against the normalization of structural injustices and seeks to build research agendas from the perspectives of those most impacted and even targeted by policies, laws, and deficit-based frameworks (Tuck, 2009).

Instead of an emphasis on disinterested or neutral research, throughout this book we recognize all research and knowledge seeking practices as being motivated by a range of interests. At one scale, we see the scholarly disciplines as having particular interests, with methodologies shaped in relation to those interests: Natural sciences use experimental methods to know the material natural world, sometimes to predict its behavior and perhaps control or affect its transformations; the social sciences and humanities use hermeneutic or interpretive methods to understand social, cultural, and historical worlds and often to contribute to their transformation. Critical theories in all these disciplines question their own foundations and are interested in using all methodologies necessary to understand and grapple with the material and ideological structures of oppression woven into the social, cultural, historical, economic, and material orders, aiming to enable the emancipation or freedom of the people who are denied their humanity within those structures (see Habermas, 1968).

How Is Research Mediated by Systems of Power?

In her pivotal text, *Decolonizing Methodologies: Research and Indigenous Peoples*, scholar Linda Tuhiwai-Smith writes, "'Research' is probably one of the dirtiest words in the indigenous world's vocabulary" (1999, p. 1). This view of research comes as a shock to many scholars who regard research as an unadulterated good, or at least as fundamentally neutral. In fact, viewing knowledge production only in a positive or neutral light erases a long history of research conducted through Western epistemological frameworks that construct deficit, harmful, and even violent narratives of Indigenous peoples and people of color. For example, see critiques of Alice Goffman's ethnographic research with Black men in Philadelphia (Lewis-Kraus, 2016) and Audra Simpson's (2011, 2016) critiques of anthropological representation; see also critiques of damage-centered analyses (Calderon, 2016; Tuck, 2009).

Western epistemic frameworks have been imbued with legitimacy through the application of disciplinary or field-specific methodologies that seem to yield warranted

findings, yet with sometimes egregious and still pervasive ideological and material impacts on affected communities. From the perspective of colonized peoples as well as marginalized communities that have often been regarded only as "research subjects" but not knowers or producers of knowledge, then, research has served as a tool of the powerful and in support of interests that have long damaged their families, modes of life, and lands (Tuhiwai-Smith, 1999).

A key takeaway is that research is always a socially situated and mediated practice. As scholars, we inherit the traditions of our particular discipline(s), including those that illustrate the intersections of knowledge and power, despite the long-held attempts to enact ideals of research as a purely objective and neutral practice.

Critical scholars across disciplines, including the natural sciences, have elaborated on the socially and culturally situated as well as inter/intra-subjective nature of knowledge and knowledge production (Barad, 2007; Haraway, 1988; Tuhiwai-Smith, 1999; Wynter, 2003). These arguments call into question how purported claims of neutrality and objectivity in research have been weaponized to veil the ideological assumptions and power embedded in all research. As a counterstance to the premise of absolute objectivity, Harding (2008) argues instead for the development of practices that cultivate "strong objectivity." That is, by engaging distinct standpoints both within and across research collaborations, scholars can illuminate how all knowledge is mediated socially, culturally, politically, and historically. This deliberate engagement of the situatedness of all knowledge claims, their reach and their limits, then, is part of a necessary practice to develop counterhegemonic knowledge claims. As we will continue to elaborate, the situatedness of research, in part, contributes to the ethical complexities of research for justice.

What Is Community-Engaged Research for Justice?

University researchers are increasingly shifting their practice to be responsive to the complex histories both of academic disciplines and of larger community contexts collaborating with community partners—from community-based nonprofit organizations to schools and government agencies and local social movement activists and community leaders—to conduct research to address social challenges (see, for example, Fine, 2021; Glass & Stoudt, 2019; Guishard et al., 2021; Strand et al., 2003; Tuck & Guishard, 2013; Warren, 2018).

Engaged scholars aim to transform social science and humanities research "to an activity done in public for the public, sometimes to clarify, sometimes to intervene, sometimes to generate new perspectives, and always to serve as eyes and ears in our ongoing efforts at understanding the present and deliberating about the future," as geographer Bent Flyvbjerg explains (2001, p. 166).

Engaged research challenges traditional conceptions of research in multiple ways: reconfiguring conventional researcher–subject relationships and power dynamics in

research; reimagining the role of research and the university in social change efforts; refashioning how research questions and design processes are constructed and practiced; and redefining the interrelationship between ethics and knowledge production, dissemination, and mobilization (see Sidebar 5).

Engaged scholars have also contributed to deepening and expanding conceptions and practices of rigor in research. For example, Fine (2008) pushes against discourses that prioritize quantitative designs to support the generalizability of studies by offering a notion of "provocative generalizability" to indicate how knowledge that is deeply meaningful within a local context can reveal structural inequities and evoke change. Similarly, Tuck and McKenzie (2015) and Lather (1991) extend understandings of the warrants with the concept of "catalytic validity," which considers the meaningfulness of the research to the communities and collaborators as a stronger measure of validity. These concepts illustrate how engaged research is not just about the inclusion of more people in the research process, but about how meaningful engagement deepens understanding and builds power to enact change.

Sidebar 5

Community-Engaged Approaches: Reclaiming Research for the "Public Good"

Some engaged scholars argue that, in addition to the benefits this research may bring to particular communities, there is potential for engaged scholarship to provide a strategic way to restore public faith in universities at a time when privatization trends in higher education undercut the notion of universities as public goods. Others argue that collaborative and community-based forms of research can intentionally disrupt certain problematic and extractive university traditions of knowledge formation and institutionalization, and thereby enable scholars to resist co-optation and develop alternative approaches. These critical modes of engaged scholarship call attention to the founding and functioning of universities in relation to processes of colonialism and racial oppression, foregrounding questions about how current research and practices within institutions of higher education serve to perpetuate and/or disrupt systems of injustice (Andreotti et al., 2015; Fine & Torre, 2021; Tuck & Guishard, 2013).

We believe that by directly grappling with these historical and ongoing intersections between ethics, knowledge production, and institutions of higher education, there is a greater chance that universities and researchers will fulfill the democratic commitments, values, and mission of both public and private universities. We also believe that by bringing these matters more explicitly into the professional communities of practice that support scholarly development, attention to ethics might become more infused throughout all research and scholarly activities.

Research for Justice

We use "social justice" and "justice" as contingent and contested placeholders for the political, epistemological, and ethical orientations that animate collaboration in and through these research projects. We also use "social transformation" and "transformation" to convey that there are different goals for change beyond, or different from, justice framings, as well as different theories of change about how to work toward social justice of all kinds (Tuck & Yang, 2018). There are multiple visions and hopes for the future that inform various scales of and demands for social change, as well as for the activism and scholarship that will undergird more just futures. Not all research that falls under the broad realm of "engaged research" or research toward "social justice" or "transformation" may be compatible in its desires and theories of change.

"Engaged research" thus takes many forms, and its variations have been called activist scholarship (Hale, 2001, 2008), critical participatory action research (Fine & Torre, 2021), decolonized methodologies (Donald, 2012; Gill et al., 2012; Tuhiwai-Smith, 1999), action research (Brydon-Miller, 2008), and various forms of public scholarship, such as usages like public anthropology and public sociology (Beck & Maida, 2015; Burawoy, 2005; Hedican, 2016); this is only a sampling, each with different foundations, orientations, and commitments. Projects oriented toward justice can range from reform to revolutionary approaches and address all dimensions of social life: human health, environmental health, education, economics, politics, housing, and more (see Ellison & Eatman, 2008). We are less concerned with parsing out distinctions in naming and focus, and we instead offer a framework for ethics that will appeal to practitioners across multiple forms of engaged scholarship.

In their foundational article "Decolonization Is Not a Metaphor," Eve Tuck and K. Wayne Yang (2012) explain that "decolonization" is a framework increasingly mobilized by educational researchers and others to describe a wide range of political and research projects, but it is sometimes mobilized in merely metaphoric ways, diluting its meaning and connection to efforts to "repatriate Indigenous land and life" and to dismantle structures of settler colonialism. Notions of social justice and transformation are even broader and can run into the same danger of empty signification or metaphoric tendencies. However, we purposefully use umbrella terms like "social justice," "justice," "social transformation," or "transformation" to be capacious in our inclusion of many different conceptions of justice, equity, and decolonization since they all in various ways are caught up in the ethical and epistemological entanglements of engaged scholarship. There are some good ethical reasons for researchers to be specific in the terminology and visions of social change that animate their particular collaborations.

Collaboration and Community Engagement

If terminology such as "engaged research," "social justice-oriented research," and "research for transformation" reflect the diversity of hopes, dreams, and visions for better lives that animate research and researchers, then adjectives like "collaborative," "community-based,"

and "participatory" similarly convey diverse theories of change and the role and shape of research efforts in addressing injustice. Once again, we use these terms broadly and capaciously due to their infusion with ethical matters, and we hope the resources in this book specifically help with those dimensions.

There are considerable differences in the ethical valences within the variety of methodological practices, theoretical approaches, and social change applications among community-based and collaborative modes of research. For example, collaborative research might describe a project in which food-service workers create and administer surveys and focus groups with other workers about the labor conditions and challenges they face in their workplaces to inform local labor policy advocacy. Or perhaps a group of university researchers collaborates with a local nonprofit organization to investigate and understand how the organization's employment training programs impact housing and health for the low-income families they serve.[1] As these examples hint, each situation may pose a range of ethical considerations that may exceed the scope of attention of standard research ethics review and procedures.

We use "collaborative" and "community engaged" to refer broadly to collaborations among researchers and community members who are coresponsible in meaningful ways for some significant portion of the research process. This coresponsibility includes forms of labor (e.g., child care, logistical coordination, reproductive labor, etc.) that may not be understood as central to the research and yet makes these collaborations possible. We also intend to highlight the ethical importance of working collaboratively and intentionally on questions and concerns generated in specific geographic locales, social justice movement spaces, nonprofit organizations, governmental agencies, and other institutions addressing injustices on various scales. These research modalities also have myriad labels in different disciplinary literatures, including community-based participatory research (Banks et al., 2013; Castleden et al., 2012; Israel et al., 2001), participatory action research (Cahill, 2007; Fine, 2006, 2021; Gaventa, 1991), youth participatory action research (Cerecer et al., 2013; Flicker, 2006; Romero et al., 2016), and Indigenous-led research (David-Chavez & Gavin, 2018), among many other terms.

Given this diversity of language and practice across a range of disciplines, we use terms such as collaborative and community-based as interchangeable adjectives to describe these myriad forms of research. The focal communities in the research partnerships of this work have been structurally or materially marginalized and silenced in policy and political debates, including those that directly affect them. All too often, these same exclusions play out, too, in conventional research about these communities (Fahlberg et al., 2025). Marginalized communities are often made legible in both public and scholarly discourse by such characterizations as low-income or low-wage workers; racially, culturally, and linguistically diverse communities; formerly incarcerated adults and youth; and more. We will use generalized descriptors such as "marginalized" or "disadvantaged" to invoke a causal direction to the historical plight of vast numbers of people in ongoing struggles against state-sanctioned and structural harms. At minimum, this requires a kind of moral humility, responsibility, and accountability on the part of

the structurally privileged, and a need for resoluteness and community on the part of the marginalized and disadvantaged.

There are efforts to find common ground to support these emerging collaborative and community-based modes of inquiry. At times, this has included interdisciplinary dialogue that yielded increased institutional support, funding opportunities, and other openings to prioritize community-engagement in research (e.g., such as the work that supported the development of this book), to the gutting of these efforts with the rise of authoritarian political regimes. As more and more students and scholars adopt and adapt collaborative and community-based research toward justice and transformation, more relevant guidance is needed to address the distinctive ethical quandaries that engaged researchers and collaborators will face. These modes of inquiry both reproduce and disrupt conventional research practices and bring to light a host of significant ethical questions about the enterprise of research more generally.

Despite variances in projects, in visions of change, and in research methods, we hope that the considerations we raise, the praxis pauses we take time for, and the ethics stories we offer for reflection all resonate with you, our reader, someone seeking to participate in research that involves communities in addressing the most pressing problems of our time. Current and future generations need ethical guidance in doing this work, and this book is a companion for the journey.

Endnotes

1. These examples come from projects that received "seed funding" to support early development of research collaborations by the University of California, Center for Collaborative Research for an Equitable California (CCREC).

Chapter 2

Procedural and Institutional Research Ethics

Have you designed an informed-consent form for research participants or been asked to provide informed consent as a research participant? Perhaps you have read the code of ethics in your academic field or profession, learning about the standards for research ethics within your discipline.

For many academics in the United States and Canada, talking about research ethics means talking about the formalized ethical frameworks and processes connected with institutional review boards (IRBs), or research ethics boards in Canada (see Castleden et al., 2012; Lewis et al., 2025; van den Hoonaard, 2002, 2003). These institutional systems significantly shape research ethics practice, training, and pedagogy. Indeed, in interviews conducted for this project, participants emphasized that ethical reflection was often synonymous with IRB approval processes in their training and practice.

While IRBs serve an important role in safeguarding the rights of research participants, these procedural forms of institutional research ethics review do not encompass the depth and scope of ethical matters and dilemmas that emerge through all forms of research, especially in community-engaged approaches committed to justice. In this chapter, we provide a critical history of research ethics institutionalization, including egregious abuses of people through research that led to the establishment of IRBs. We then review critiques of IRB implementation, some of which have led to changes in research ethics legislation and university systems. We conclude with offering guidance for navigating IRB processes while remaining attentive to the need to engage and deepen an ethical practice. This is especially important for community-engaged scholars committed to justice as many formalized and procedural ethics frameworks do not sufficiently attend to the specificities of community-based work.

Codifying Research Ethics: A Brief Critical History

Formal debates about research ethics emerged relatively recently among scholars across academic disciplines and in communities where research has taken place. Across many research ethics texts and officially approved training modules, emergent researchers learn

about key periods, cases, and international documents that are foundational to current IRB processes (e.g., Bankert & Amdur, 2005; Faden et al., 1986). We present a critical reading of this narrative here, emphasizing the importance of these interventions and their elisions.

The Nuremberg Code and the Declaration of Helsinki

A critical period for public and institutional debates as well as political action occurred between the 1950s and 1970s in the wake of public revelations about the horrors perpetrated by health professionals serving the German Nazi regime and later in a series of high-profile ethics cases involving U.S. public health and psychology researchers. This arc of events is often cited in histories of research ethics, including training modules like the "Protecting Human Subjects" training tool developed in 1986 by the U.S. Food and Drug Administration and in texts like *Institutional Review Board: Management and Function* (Bankert & Amdur, 2005) and *A History and Theory of Informed Consent* (Faden et al., 1986).

The first internationally recognized research ethics document is the Nuremberg Code, which was developed in 1947 at the end of a special Nazi war criminal trial for medical professionals; the trial revealed shocking details of experimentation on human subjects during the Holocaust. The code identified 10 basic principles for conducting ethical medical research with human subjects (see Sidebar 6). The first principle requires researchers to obtain "voluntary, competent, informed, and comprehending" consent from human subjects and is often cited as a key contribution that shaped later ethics policies (see, for example, Faden et al., 1986).

Sidebar 6

Nuremberg Code (1947)

1. The voluntary consent of the human subject is absolutely essential.
2. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected;

and the effects upon his health or person which may possibly come from his participation in the experiment.

The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.

3. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.
4. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.
5. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
6. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except, perhaps in those experiments where the experimental physicians also serve as subjects.
7. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
8. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
9. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.
10. During the course of the experiment the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.
11. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill and careful judgment required of him that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

In 1964, the World Medical Association (WMA) developed the Declaration of Helsinki, another foundational global document that specified additional principles for ethical biomedical experimentation with human research participants. The Declaration of Helsinki aimed to address public distrust in biomedical research, particularly given the abusive medical experimentation and torture revealed at the Nuremberg trials. It was understood that this trust needed to be reestablished by the medical community at an international scale in order for people to participate in medical research that would be the basis of continued advancements in medicine and public health (Faden et al., 1986). Therefore, the guiding principle of the Declaration of Helsinki included a binding oath for all physicians that the health of each patient would remain their first consideration. The World Medical Association continues to revise the original declaration to further articulate ethical principles that guide the medical community in conducting research with human participants (e.g., see World Medical Association, 2024).

Research Ethics in the United States: The Tuskegee Tipping Point

A number of highly controversial cases in the United States provoked further critical public scrutiny and legal-political debate about research ethics. This included the case of psychologist Philip Zimbardo's study that allowed students at Stanford University to mistreat one another in what became widely referred to as the "Stanford Prison Experiment," often cited to highlight the potential for both short- and long-term negative physical and psychological effects of research. Zimbardo himself recognized these problems (Perlstadt, 2018; Zimbardo, 1973; Zimbardo et al., 1999). Also during this time, sociologist Laud Humphrey's study of closeted homosexual activity raised questions about deception, violations of privacy, and the absence of consent by those being studied (Humphreys, 1970; see also Lenza, 2004).

The tipping point in the United States was an exposé of the egregious exploitation of African American men for nearly 4 decades in the now infamous experiment often referred to as the "Tuskegee Syphilis Study." Initiated in 1932, researchers and physicians employed by the U.S. Public Health Service wanted to follow the progression of syphilis in Black men based on a racist premise that the disease would manifest distinctly in African Americans (Loue, 2000). Researchers recruited around 600 people who were sharecroppers living in poverty in Tuskegee, Alabama, of whom two-thirds had syphilis.

The men were recruited on the premise that they would be receiving free medical care, including treatment for "bad blood," a colloquial term for a range of illnesses, in addition to free meals when receiving their medical exams, transportation to the clinic to be seen, as well as burial stipends paid to their loved ones upon their passing (Washington, 2006). All of these incentives were significant, given that the men were surviving life within already racially and economically exploitative contexts as sharecroppers.

The men were not told that they were being studied, and the physicians, in fact, never provided medical care. These omissions, forms of deception, and coercion were problematic on multiple levels in and of themselves, reinforcing and extending the racist beliefs underlying the design of the study. These injustices persisted in an even more disturbing way: Physicians discovered that penicillin would effectively treat syphilis in the 1940s, and by 1947, the antibiotic was widely prescribed and used to cure the disease. Yet rather than provide the available and necessary treatment for the men, the researchers actively withheld treatment for 25 years, until 1972 (Washington, 2006).

The violent scale and range of harm must be emphasized: Publicly employed health officials intentionally prevented African American men in Tuskegee from accessing life-saving treatment for a quarter century. In addition, this violence extended beyond the men themselves into the broader African American community as syphilis continued to spread. If it weren't for the investigative work of Associated Press journalist Jean Heller, who discovered what the public health officials were doing and broke the story in a journalistic exposé, the violence would have continued even beyond the death of the men. As medical ethicist Harriet Washington (2006) argues, the public health researchers likely aimed to perform investigative autopsies, making the men "living cadavers, more valuable to American medicine dead than alive" (p. 164).

Washington's (2006) meticulous research documents the entanglement of medical science and slavery in the United States dating back to the 18th century. Physicians in the U.S. colonies relied not only on the wealth extracted from the system of chattel slavery to finance their research and medical developments, but they also relied on Black bodies to supply the "clinical material" for their experimentation (Washington, 2006). The examples Washington documents are painfully extensive, spanning centuries and similar scales of harm, from experiments conducted on enslaved peoples to 19th-century medical schools boasting to potential applicants of the learning opportunities from the cadavers of both newly deceased and exhumed Black people. The infamous James Marion Sims, the so-called "Father of Gynecology," spent years experimenting on enslaved African American teenage girls to develop and perfect medical instruments and surgeries, causing irreparable bodily harm through tortuous procedures, oftentimes conducted without any anesthesia (Washington, 2006).

Abuses within research practices are not only historical: They continue to persist in the present through numerous examples of neglect, harm, and dismissal of Black people when aiming to access medical care (Washington, 2006). Given these violent and ethically unjustified practices in the history of medical experimentation on Black people in the United States, spanning the colonial period to the present day, a multigenerational mistrust in research and medicine persists amongst many members of the Black community, as well as with Indigenous Nations and other communities of color.

In a notable case, Havasupai tribal members reached a settlement in their complaint against the University of Arizona (*Havasupai Tribe v. the Arizona Board of Regents, 2004*) regarding the violation of their civil rights and rights as research subjects. They

had given blood samples for research that focused on high rates of diabetes in their community, research they had actively pursued via a trusted academic anthropologist who had worked with their community. Members of the Havasupai later learned that the samples had also been obtained and used for dozens of other studies unrelated to diabetes without their knowledge or expressed consent. As a result of this breach of trust and research ethics misconduct, tribal members banned University of Arizona researchers from working with the community (Garrison & Cho, 2013; Harmon, 2010; Sterling, 2011).

To this day, people continue to enact large-scale violence that is rooted in and perpetuates racist ideologies through the manipulation of research. In January 2026, the *New York Times* broke a story that researchers had gained access to data (collected by researchers in another study) in order to "argue for the intellectual superiority of white people" (McIntire, 2026). The genomic data co-opted for a racial science agenda had originally been provided by the families of over 20,000 children as part of a longitudinal study known as the Adolescent Brain Cognitive Development, or ABCD study (Breslow & Smith, 2026).

Thus, while the Tuskegee Syphilis Study remains an outrageous harm we must study and understand, it is also part of a deeper, more pervasive and continuing legacy of violence conducted in the name of research. To understand Tuskegee as a mere aberration is to enact a process of "colonial unknowing" that erases how many academic disciplinary formations in the United States, in addition to the biomedical field, have been predicated on both racial and colonial violence (Sabati, 2018).

Institutional Review Boards (IRBs): The U.S. Government's Response

Following the journalistic exposé of the U.S. Public Health–sponsored Tuskegee Syphilis Study, U.S. Senator Edward Kennedy headed an investigation that led to congressional hearings and the passage of the National Research Act in 1974. This act established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and led to the development of institutional review boards (IRBs) to regulate all research involving human beings and funded under the former federal Department of Health, Education, and Welfare (now Department of Health and Human Services). Although the law pertains only to federally funded research, it quickly became standard practice to have all research involving human subjects reviewed by IRBs.

The National Commission later released a series of reports and protocols concerning ethical standards for what were described as particularly "vulnerable subjects," released in successive guidelines: "Research on the Fetus" (1975), "Research Involving Prisoners" (1976), and "Research Involving Children" (1977). Perhaps the best known of these subsequent reports is the 1979 *Belmont Report* (Office of the Secretary, 1979), named for the Smithsonian Institute conference center where the Commission convened.

Table 2.1 ■ Belmont Report Principles (1978)

Belmont Principles		
Principle 1: Respect for Persons	**Principle 2: Beneficence**	**Principle 3: Justice**
Requires researchers to secure voluntary, comprehending, and informed consent	Requires researchers to systematically assess the nature and scope of the risks and benefits of research, and to communicate risks and benefits to potential research subjects or participants	Requires fair research subject selection procedures and outcomes, neither disproportionately harming nor benefiting members of any particular social, racial, gender, or ethnic group

The *Belmont Report* identifies three "basic ethical principles underlying the acceptable conduct of research involving human subjects"— respect for persons, beneficence, and justice. Each principle is connected to specific research ethics practices (see Table 2.1).

The recommendations of the Belmont Report were turned into law through the Code of Federal Regulations, or 45 CFR 46. Subpart A of the federal code is generally referred to as the "Common Rule," as it describes the legal protections required for all human subjects who researchers may seek to participate in research. There are additional protections elaborated for particular groups such as minors, incarcerated people, pregnant people, and other groups deemed "vulnerable" to unethical practices like coercion, which are outlined in subparts B, C, and D of the policy.

From Ethical Principles to Policy and Practice

Early IRB practitioners faced the complicated task of interpreting and implementing federal laws to develop infrastructures and processes for reviewing research at universities across the United States (Bankert & Amdur, 2006). Universities also developed new offices of research and other administrative bodies to facilitate institutional ethics review to be compliant with federal laws.

As noted, although the Common Rule only requires IRB review for federally funded research with human subjects, universities generally require review of all research involving human subjects, except studies that fall under specified exemptions. Additionally, many scholarly publications, including dissertations and journal articles, require submission and citation of IRB approvals of research. The 1980s and 1990s therefore marked a significant period, as the core institutional structures and practices were developed to create these procedures to address research ethics. During this time, academic professional associations also established ethics committees to develop core principles and codes of ethics within their respective disciplines and fields.

Praxis Pause 2

Codes of Ethics in Your Discipline or Field

Take a moment to research the code of ethics for your discipline or field. These are usually located somewhere on the websites of the major professional associations (e.g., American Psychological Association, American Sociological Association, American Anthropological Association, American Educational Research Association, Association of American Geographers, American Studies Association, and more).

Once you find the code of ethics, open it up and read through it. Reflect on and discuss these questions:

1. Which ethical principles or frameworks are named for guiding research?
2. Which ethical practices are named for guiding research?
3. Does the code of ethics address community-engaged research? If so, how are the ethical guidelines similar or different to the broader code?
4. Does the code of ethics address issues of power in research, or the history of the discipline/field in addressing or contributing to systems of power? If so, consider how these issues are framed. If not, consider what else may be missing.

Critiques of Procedural Ethics

As these research ethics frameworks and procedures were being formalized, many scholars also began to experience, analyze, and critique what was becoming the highly procedural and narrowly institutionalized forms of attention to research ethics. Pressed most strongly by researchers in the humanities and social sciences, these critiques focus on the overdetermination of biomedical, experimental, and objectivist conceptions of research and research ethics. Critiques were also developed about the bureaucratic role of IRBs and the prioritization of institutional defense against liability rather than substantive questions of ethics in these disciplinary approaches to research (see Sidebar 7; e.g., Lederman, 2006a, 2006b).

Debates about IRBs and their focus on procedural milestones in research ethics continued to unfold in journals like the *Journal for Empirical Research on Human Ethics Review*, *Academic Ethics Review*, *Research Ethics*, *IRB: Ethics and Human Research*, and a growing number of monographs and edited volumes on the topic (Stark, 2012; van den Hoonaard, 2002, 2011). Scholars identified a methodological mismatch for the social sciences and humanities when research ethics is elaborated from a model of research premised on positivist and postpositivist biomedical or psychological experimental approaches. Other scholars argued that IRBs were merely a mechanism for protecting their institution from legal liability and failed to adequately address even those issues in its limited scope, and

furthermore, this at times actually impeded the development of new knowledge (Bledsoe et al., 2007; Feeley, 2007; Guta et al., 2013; Heimer & Petty, 2010; Ribeiro, 2006).

Sidebar 7 provides an overview of some of the key critiques developed by scholars across the social sciences and humanities about the methodological mismatches with IRB principles and procedures, and it also identifies how these methodological misalignments translated into bureaucratic and legalistic mechanisms, leading many scholars in these disciplines and fields to ask, who do IRBs actually protect?

Sidebar 7

Critiques of the IRB Regime

After the introduction and ascendancy of institutional review board review and approval procedures, many scholars critiqued the ways universities and ethics boards interpreted their role and reach. We offer a brief summary of their critiques in this sidebar; and as noted, some of these critiques were addressed with the 2018 revisions to the Common Rule and resulting shifts in ethics review processes.

Methodological Mismatch

- IRBs rely on a positivist framework or experimental approaches to research (e.g., Bledsoe et al., 2007; Guta et al., 2013; van den Hoonaard, 2002).
- Preliminary review is incommensurate with research approaches in social sciences, such as semistructured interviews and ethnography (e.g., Halse & Honey, 2007).
- Unlike experimental or clinical methods, social science methods, such as asking questions or reading and interpreting documents, are ordinary acts that occur in regular social interactions, rendering potential harms minimal and inconsequential (e.g., Dingwall, 2008; Heimer & Petty, 2010).
- Even when social science methods present ethical problems and risks, ethical considerations are different from biomedical and psychological research and deserve a different regulatory process (e.g., Feeley, 2007).

Bureaucratic and Legalistic Function of IRBs

- IRBs shifted from protecting human subjects' rights to protecting the universities and risk-averse institutions against legal liabilities (e.g., Klitzman, 2012; Stark, 2012).
- IRBs interfere with research relationships through their imposition of legality versus other forms of relationality.

- IRBs are part of a broader trend toward regulatory regimes at institutional and state levels.
- IRBs can function as gatekeepers for research and the advancement of knowledge, not only slowing research down but even operating to censor research or infringe on researchers' rights to academic freedom (e.g., Bledsoe et al., 2007; Dingwall, 2008; Katz & Feeley, 2007).

Many scholars channeled their critiques into nationwide discussions around revising the Common Rule in the 2010s (e.g., National Research Council, 2014), which included the selection of national commissions to study and revise these procedures, with broad implications for social science and humanities research, culminating in major revisions to the Common Rule that were implemented in 2018. The 2018 revision expanded the exemption categories, clarified the elements and procedures for informed consent, and established guidelines for continuing reviews. These changes helped to address many of the concerns about a mismatch between IRB practices and research methodologies that had negatively impacted a wide range of research in the social sciences, humanities, and community-engaged approaches.

As a result of the Common Rule revisions, most social science research is exempt from the full IRB review (Riley & Akbar, 2017). The determination is still made by each IRB, which conducts initial reviews of research applications to decide which level of review is required, taking into account specific criteria such as the populations included and types of data collected. For research that poses minimal risks and that qualifies for an expedited review, the IRB ensures that researchers meet their obligations to respect the rights of research participants through informed-consent procedures, and approved methods of collecting data and secure storage.

While these changes alleviate some of the IRB-related epistemological and institutional barriers experienced by scholars in the humanistic social sciences, it still leaves the complex issues that shape the ethics of research largely unaddressed, particularly when it comes to community-engaged research for justice (Newman & Glass, 2014). As the subsequent chapters elaborate, we offer additional avenues for ethical reflection and guidance beyond the necessary considerations that fall under the purview of an IRB.

Addressing Racial–Colonial Legacies in Research

As discussed in Chapter 1, research is mediated by systems of power. Yet when many students learn about research ethics and IRBs through canonical texts that emphasize egregious cases of harm, these power dynamics are often obscured, and the specific racial–colonial legacies of research in the United States are elided (Sabati, 2018). Important counternarratives have been developed, such as in the studies conducted by

Harriet A. Washington (2008) or in the foundational work of Linda Tuhiwai-Smith (1999). Additionally, recirculations of common narratives of research ethics often describe ethical lapses as the fault of negligent individual researchers within an otherwise neutral or benevolent framing of research and of universities, but this veils how knowledge production practices are mobilized within structures of domination and exploitation through cultural, social, legal, economic, and political processes.

For too many communities, the impacts of research across generations have been grave and continue to have lasting effects into their everyday lives. We therefore have a responsibility to attend to communities' experiences of research and research ethics to guide our ethical obligations to our collaborators. When we understand the complex ethical dimensions of knowledge production practices and how they are situated in larger historical, social, cultural, and psychological dimensions of experience, we also have to question how the historical narratives about research ethics themselves are formed and framed, particularly when research is portrayed as an unquestioned good and when ethical breaches are characterized as mere instances of individual malfeasance.

Physician Henry K. Beecher made a similar argument in a controversial and now classic and touchstone publication in the *New England Journal of Medicine* in 1966, where he documented the pervasive history of exploitative and unethical research enacted in the name of science. He cited 22 cases of research conducted without informed consent—or sometimes without any sort of consent—including research that withheld treatment for those suffering from rheumatic and typhoid fevers, research that infected mentally disabled children with hepatitis, and research that injected live cancer cells into unknowing subjects (El-Hai, 2017).

Writing in response to the framings of the Nuremberg trials of the 1940s, Beecher urged people not to feel comfortable with narratives that isolated the atrocities enacted through research to the few often-cited cases. Even with the clarity of ethical insight that undergirds Beecher's warning, it also discloses the ways in which additional layers of ethical reflexivity, responsibility, and accountability are necessary. In a twist that was never publicly acknowledged, Beecher himself had been a leader in U.S. top-secret psychological warfare studies, in which LSD and other hallucinogens were used to drug people in unethical searches for "truth serums" and battlefield weapons; further, they had solicited input from Nazi doctors in these "studies" (El-Hai, 2017).

This history points toward the enduring importance of developing a more adequate ethical understanding, formation, and professional practice for scholars. By considering these many deep-reaching issues regarding the ethics of research, we aim to cultivate ethical research practices attuned to the full spectrum of ways that higher education, research, and knowledge production activities have impacted the lives of different communities—from supporting ongoing domination and exploitation of Indigenous communities and communities of color since colonization to disrupting harmful practices and power dynamics through efforts to form a more just society

Engaging Your Ethics Review Board and Professional Code of Ethics

The implementation of the 2018 changes to the Common Rule eliminated many of the barriers within the IRB processes that had once failed to meaningfully account for the distinctive methodological approaches within the social sciences, humanities, and community-based research approaches. While the next chapters will continue to elaborate the ways in which the ethics of research extend beyond the procedures of securing your IRB's approval and carrying out its mandates, IRB protections and procedures remain a necessary and important component of the research process. At the very minimum, they help ensure that some basic rights of human research participants must be respected.

The specifics of navigating procedural ethics processes will be contextual to your research and depend on many factors. In addition to securing IRB approval from your campus or institution, your research may necessitate review from a local research ethics review board, such as a tribal IRB, community-based IRB, or the specific school district where you will do your research. Given this, we encourage you to approach institutional research ethics review processes early, strategically, and relationally; here, we offer a few touchstones to inform a relational and situated approach.

First, we encourage you to assess the landscape of institutional ethics and procedures on your own campus, in your field of study, and in the communities where you work early on as you begin to collaborate with your partners. Institutional review boards function differently from one institution to another and from one board administration to another, sometimes even varying quite widely in their determinations and timelines. Some IRBs are highly detail-oriented, focused on getting particular bureaucratic details just right, while others take a broader view to assess the overall research plan and ensure that they are fulfilling their legal obligations and that affiliated researchers are respecting the rights of research participants. Some IRBs have significant experience reviewing applications for community-engaged research for justice, while others maintain a view of what constitutes research and research ethics that may even exclude these approaches from consideration. Getting to know your own campus's IRB culture can help you to determine how to position your work and engagement with the IRB.

Second, based on what you learn about the landscape of institutional ethics at your university, in your field, and in the community where you work, you can choose from a suite of strategies about how to describe your project in relation to institutional ethics. For some, the most prudent approach is to be truthful and concise, sharing what is necessary to fulfill the procedural demands. For others, there may be opportunities to dialogue with your ethics officer or research ethics review board, join the ethics review committee, or collaborate in other ways that help educate your IRB on the nuances of community-engaged approaches to create more informed and responsive procedures (Lederman, 2007).

Third, we encourage you to look up your disciplinary or field-specific guidelines on research ethics (see Praxis Pause: Codes of Ethics in Your Discipline or Field, earlier in

this chapter). This will give you a sense of the principles, frameworks, and practices that are central within your discipline and the basis of its standards around ethical research. In some disciplines, codes of ethics can be found on the website of national and international disciplinary associations. Look for any documentation or scholarship on how these codes have changed over time, as well as whether or not they provide specific guidance on community-engaged research. Notice what is present and what is absent, as it is just as important to learn from what guidance exists as well as the gaps. In addition, pay attention to any mention of a need to address particular harms that have been extended against communities through your discipline or field. When this is absent, seek scholarship that critically historizes research in this way.

Finally—and central to this text—researchers and community partners must recognize that ethical deliberation does not begin or end with institutional ethics review, nor with the signing of consent forms. The IRB process and its principles, frameworks, and procedures can be opportunities for researchers and partners to reflect on and articulate the meaning of respect, consent, justice, and the other ethical dimensions of their research plans, and thereby anticipate some potential ethical challenges. As we explore in further detail in the chapters to come, engaging in ethics as praxis means that the ethics of research precedes, endures throughout, and extends beyond the formal procedures of securing IRB approval and consent from your partners and participants.