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Jessica Fahim July 7, 2025

Constructing [In]visibility: Racial categories, MENA, and the Architecture of Healthcare

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Abstract

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This thesis explores how racial classification functions as a form of structural power that shapes visibility, recognition, and access to care in U.S. healthcare and public policy. Focusing on Middle Eastern and North African (MENA) populations, it argues that their persistent classification as "White" is not a neutral bureaucratic decision, but a politically motivated act that produces ethical harm. By situating MENA classification within a broader history of legal and administrative governance—through naturalization cases, census policy, and public health data infrastructures—this project argues that racial categories do not simply reflect social realities but construct them in ways that determine which communities become visible, countable, and actionable within systems of care. The consequences of this exclusion are not abstract: MENA communities are routinely left out of public health research, denied targeted interventions, and rendered ineligible for funding and support. This thesis positions these outcomes as a form of ethical harm, one that bioethics must take seriously. It challenges the field to move beyond descriptive accounts of disparity and instead confront the classificatory regimes that produce and sustain them. In doing so, it reframes racial classification as a site of governance and ethical inquiry—calling for a bioethics that recognizes its own entanglement in systems of power, and that seeks not merely to mitigate harm but to expose and unsettle the conditions that make it possible.

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I. Introduction

"Human identity is not only not natural and stable, but constructed, and occasionally even invented outright." — Edward Said

"And yet nonwhite bodies do inhabit white spaces; we know this. Such bodies are made invisible when spaces appear white, at the same time as they become hypervisible when they do not pass, which means they 'stand out' and 'stand apart.'" — Sara Ahmed

To speak of race in the context of healthcare is to speak of both visibility and its calculated absence. It is to confront how systems of classification determine who is recognized, who is protected, and whose needs are met—or structurally neglected. These reflections by Edward Said and Sara Ahmed are not theoretical scaffolding for this thesis, but rather provocations that illuminate the ethical stakes of racial categorization in American healthcare. As Said reminds us, identity is not a stable truth to be uncovered but a political construct shaped through systems of power. Ahmed extends this insight by showing how nonwhite bodies are made conditionally visible: obscured when their presence conforms to white-coded spaces, and hypervisible when they disrupt or refuse to pass. These dual processes are not contradictory; they are mutually reinforcing, creating a cycle that legitimizes exclusion through selective recognition.

Beginning with these provocations matters. Said and Ahmed's reflections surface the question this thesis seeks to examine in concrete, applied terms: What are the ethical and public health consequences of institutional racial classification—and what does the Middle Eastern and

¹ Edward W. Said, *Orientalism*, 25th Anniversary ed. (New York: Vintage Books, 2003), 332.

² Sara Ahmed, On Being Included: Racism and Diversity in Institutional Life (Durham, NC: Duke University Press, 2012), 42.

North African (MENA)³ case reveal about how those consequences are produced and justified? The case of MENA populations provides a powerful entry point for understanding how such technologies of power play out in medical and public health settings. This is not simply a theoretical question about how we name or see race; it is a public health issue that impacts who receives care, who is targeted for intervention, and who is systematically overlooked. In focusing on the MENA case, this thesis reveals how racial categories operate as epidermal-epistemological frameworks⁴—ways of knowing and treating bodies that are rooted in appearance, assumption, and political unity.

This paradox of hypervisibility and invisibility structures the experience of MENA populations in the United States. On one hand, they are hypervisible in contexts of national security, immigration control, and racial profiling—cast as suspect, foreign, and Other.⁵ On the other hand, they are structurally invisible in public health and medical classification, where their

³ Throughout this essay, I use "MENA" to refer to individuals who self-identify as part of the Middle East and North Africa region, recognizing that this designation is a socially and politically constructed category rather than a fixed racial or ethnic identity. The term encompasses diverse linguistic, religious, and national backgrounds—including Arabs and non-Arab, Muslim and non-Muslim communities—and its contested nature reflects broader debates about racial classification in the U.S. While "MENA," "Arab," and "Muslim" are sometimes used interchangeably in political and public health discourse, they are not synonymous. This essay uses "MENA" as the default analytic category when discussing federal classification and health data unless otherwise specified. As Jamal and Naber note, "while 'whiteness' may be invisible to those who benefit from it, it is certainly visible to those who suffer its consequences." This dynamic underscores how MENA communities are often rendered invisible by state classifications yet hypervisible in political discourse. See Amaney Jamal and Nadine Naber, *Race and Arab Americans Before and After 9/11: From Invisible Citizens to Visible Subjects* (Syracuse: Syracuse University Press, 2008), 134.

⁴ This term draws from Frantz Fanon's analysis of how racialized bodies are rendered visible and knowable through systems of power. In *Black Skin, White Masks*, he describes the "epidermalization" of inferiority—the process by which race becomes inscribed on the skin and read as social meaning. As Fanon writes, "The black man has no ontological resistance in the eyes of the white man," capturing how identity under racial regimes is imposed rather than self-defined. See Frantz Fanon, *Black Skin, White Masks*, trans. Richard Philcox (New York: Grove Press, 2008), Chapter 5; originally published as *Peau noire, masques blancs* (Paris: Éditions du Seuil, 1952).

⁵ Nadine Naber examines how Arab Americans are constructed as culturally incompatible and politically threatening within the U.S. This framing positions Arabs and Muslims as figures of national insecurity, not only through state surveillance but also through cultural discourse that normalizes their hypervisibility as threats. See *Arab America: Gender, Cultural Politics, and Activism* (New York: NYU Press, 2012), chap. 1.

formal designation as "White" renders their specific health disparities unmeasured and unaccounted for. These dynamics are not simply coexisting but co-constitutive: surveillance reinforces invisibility in healthcare, and that invisibility, in turn, normalizes the conditions of neglect.

The consequences are far-reaching. The legal classification of MENA individuals as "White" excludes them from targeted health disparity funding, underrepresents them in clinical research, and omits them from federal data collection. The disparities in cardiovascular disease, cancer outcomes, mental health access, and insurance coverage that affect MENA populations remain largely unacknowledged within formal systems, yet they have still been documented through alternative means: ethnographic studies, surname algorithms, community-based surveys, and self-identification tools. This documentation does not merely fill a data gap; it reveals the active consequences of a classification regime that filters visibility through political utility. In this context, visibility is not a neutral reflection of demographic presence, but a function of

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⁶ The OMB classifies MENA individuals as "White": "a person having origins in any of the original peoples of Europe, the Middle East, or North Africa." See OMB Directive No. 15 (1997), https://obamawhitehouse.archives.gov/omb/fedreg 1997standards/.

⁷ See New York Immigration Coalition, *Invisible in the Data: The Lack of a Middle Eastern and North African (MENA) Race/Ethnicity Category Obscures Disparities* (New York: NYIC, April 2024), https://www.nyic.org/wp-content/uploads/2024/04/Invisible-in-the-Data-The-Lack-of-a-Middle-Eastern-and-North-African-MENA-Race-Ethnicity-Category-Obscures-Disparities-compressed.pdf. The report argues that aggregating MENA communities under "White" obscures their needs, denies them equal protection, and limits their ability to raise legal challenges due to the absence of disaggregated data.

⁸ Ruha Benjamin describes race as "a kind of tool – one designed to stratify and sanctify social injustice," showing how emerging technologies like AI and data systems extend these logics by shaping who is seen, counted, or ignored. This perspective frames surveillance and healthcare invisibility as co-constitutive functions of modern systems of control. See *Race After Technology* (Cambridge: Polity Press, 2019).

⁹ The OMB declined to implement a separate MENA category despite \$7.25 million in supporting research, reflecting political priorities over scientific evidence. This omission continues to undermine the identification of Arab/MENA health disparities. See Awad GH et al., "Lack of Arab or Middle Eastern and North African Health Data Undermines Assessment of Health Disparities," *American Journal of Public Health* 112, no. 2 (2022): 209–212. https://pmc.ncbi.nlm.nih.gov/articles/PMC8802571/.

¹⁰ These forms of documentation and the disparities they reveal will be discussed in detail in Chapter 2.

whether recognition aligns with institutional priorities—preserving administrative legibility, directing resource allocation, and maintaining the normative boundaries of racial governance.

The case of MENA miscategorization¹¹ does not seek to prove that health disparities exist; it seeks to show how racial classification itself contributes to and obscures these disparities.¹² MENA populations offer a unique analytical lens: their legal whiteness paired with lived racialization exposes the limitations of conventional public health frameworks that rely on fixed categories to deliver justice. Their exclusion highlights how government tools, such as census data and research criteria, operate as instruments of control, not just description.¹³ It is not only that MENA communities are misclassified, but that classification is being used to produce and justify their marginalization. These consequences are material, measurable, and ethical. They make plain that racial classification must be examined not simply as a social construct, but as a public health issue with bioethical urgency.

This thesis unfolds in three chapters, using the case of MENA populations to show how racial classification governs, not as an autonomous agent, but as a technology embedded within legal, bureaucratic and medical institutions that administer population life. To say classification

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¹¹ I use "miscategorization" here with caution—not to suggest that a more accurate racial classification system would resolve the structural violence faced by MENA populations, but to name how institutional power disciplines visibility through the language of correction. As Sean Meighoo warns, even critiques of misrepresentation can reinscribe the very epistemologies they seek to undo, reproducing the assumption that proper recognition is possible within systems built to obscure. The problem, then, is not only that MENA populations are miscategorized—but that categorization itself operates as a colonial technology of legibility. See Sean Meighoo, *The End of the West and Other Cautionary Tales* (New York: Columbia University Press, 2016), 128.

¹² Benedict Anderson, *Imagined Communities: Reflections on the Origin and Spread of Nationalism*, rev. and extended ed. (London: Verso, 1991), 163–186. Anderson argues that the colonial census did not merely describe preexisting identities, but actively shaped and fixed them into rigid categories, producing legibility for the state while obscuring lived complexity. His analysis supports the claim that classification systems contribute to and obscure structural realities, depending on their political function.

¹³ As Steven Epstein observes, while agencies like the NIH describe racial and ethnic categories as "socio-political constructs," these classifications are still the ones "that are counted and which, therefore, effectively 'count.'" This practice naturalizes political categories and ties recognition and funding to their use. See Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago: The University of Chicago Press, 2007), 150.

governs is to foreground its role in organizing the conditions under which certain lives become actionable within public systems. Governance here is not exerted by classification itself but enacted through it—by courts, by the state, and by administrative bodies that use it to make populations intelligible for regulation, resource allocation and care.

Chapter One traces the legal and bureaucratic classification of MENA populations as White under Office of Management and Budget (OMB) standards, ¹⁴ situating this within a longer history of using racial categories to distribute rights and recognition. While race is understood as a social construct, this chapter focuses on how that construct functions as a political instrument in the case of MENA identity. It highlights the shifting, arbitrary nature of MENA classification—not as error, but as intentional governance. The contradiction between legal whiteness and lived exclusion reveals how classification operates as a mechanism through which institutions exercise structural governance. It becomes the medium by which courts, federal agencies, and public health systems organize populations. This form of governance produced both ethical harm—by denying MENA communities the recognition and respect afforded to other marginalized groups—and material harm, by contributing to their exclusion from healthcare resources, data infrastructures, and public health protections. Together, these harms lay the groundwork for understanding classification as a site of both moral injury and public health failure.

Chapter Two moves from structure to impact. It shows how classification results in concrete health disparities that remain untracked by institutional systems. This chapter uses these consequences to reframe the invisibility of MENA populations as both a public health failure and

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¹⁴ See footnote 6.

a bioethical problem—one that emerges not only from the absence of care, but from a deeper pattern of disregard embedded in how recognition itself is structured in healthcare.¹⁵

Chapter Three focuses on the ethical implications of MENA misclassification and asks how public health, and bioethics might respond to the harms identified in the previous chapters. Rather than framing reform as a resolution, it considers how interventions—such as provisional inclusion of a MENA identifier, embedded recognition in clinical care, and the support of community-led research—can expose the violence of classification. These actions do not presume to fix a flawed system but recognize that bureaucratic legibility is never neutral. A provisional category, in this context, is not an endpoint but a strategic disruption. It is a means to document harm, redistribute resources, and make visible the populations that racialized governance renders conditionally knowable. Both public health and bioethics have a role in refusing epistemic silence and insisting on accountability in how health is measured, represented, and delivered.

Taken together, these chapters show that the placement of MENA populations within existing racial taxonomies is not an error to be corrected, but a calculated outcome of bureaucratic and political rationalities. The MENA case illustrates how classification itself functions as a mode of governance—one that produces legibility, not simply in terms of

¹⁵ See Jonathan Metzl and Dorothy Roberts, "Structural Competency Meets Structural Racism: Race, Politics, and the Structure of Medical Knowledge," *Virtual Mentor* 16, no. 9 (2014): 674–690, https://doi.org/10.1001/virtualmentor.2014.16.9.spec1-1409, for more on how structural forces shape medical knowledge and contribute to the ethical invisibility of racialized health disparities.

¹⁶ Following Judith Butler and other scholars of epistemic and symbolic violence, this thesis understands harm not only as physical injury but also as the structural, discursive, and institutional conditions that foreclose recognition. In this context, classification can be injurious not through overt force but through the regulatory frameworks it authorizes.

¹⁷ As James C. Scott writes, categories that begin as "artificial inventions of cadastral surveyors, census takers, judges, or police officers" can come to "organize people's daily experience precisely because they are embedded in state-created institutions." These fictive classifications acquire power as the state acts on them. See *Seeing Like a State* (New Haven: Yale University Press, 1998), 83.

visibility, but as a mode of institutional recognition. This legibility is fabricated through shifting and contingent criteria, always tied to state interests.¹⁸

The conclusion turns to bioethics not to propose resolution, but to interrogate its role in legitimizing these classificatory regimes. This thesis does not claim that bioethics intentionally upholds racial hierarchies, but rather that it has often reproduced and stabilized their logics by appealing to frameworks presumed to be neutral. To assert ethical authority without examining these inherited assumptions risks re-inscribing the very exclusions bioethics might otherwise seek to challenge. This is the "so what" of the project: a demand that bioethics recognize its entanglement with the infrastructures it seeks to guide and begin to imagine forms of ethics that do not merely accommodate power but actively unsettle it.

¹⁸ This draws on Foucault's analysis of how modern power operates through surveillance, normalization, and examination, transforming individuals into subjects who can be known, compared, and regulated. See Michel Foucault, *Discipline and Punish: The Birth of the Prison*, trans. Alan Sheridan (New York: Vintage Books, 1995), 170–190; originally published as *Surveiller et punir: Naissance de la prison* (Paris: Éditions Gallimard, 1975).

II. Chapter 1: The Problem of Classification—Bureaucracy and the Politics of Visibility

A. Historical Foundations of MENA Classification in the United States

Beginning with the legal history of MENA classification clarifies how racial categories in the U.S. have been deliberately constructed to serve political and institutional aims. ¹⁹ The invisibility of MENA populations in federal health data and research emerges not from mere omission, but from the legal frameworks that first rendered them—if only partially—legible to the state. ²⁰ This subsection traces how racial classification, far from neutral, has always been a means of determining who is seen, counted, and included in the nation. This legal backdrop continues to shape how healthcare and public health operate within the enduring structures of racial governance. ²¹

Racial classification in the U.S. has historically regulated access to citizenship, voting rights, land ownership, and public services. The Naturalization Act of 1790 limited citizenship to "free white persons," excluding enslaved individuals, free Black people, Indigenous peoples, and other nonwhite groups.²² This racial prerequisite for naturalization did not simply reflect an early preference for whiteness; it actively articulated the nascent nation's will to define itself through exclusion, positioning whiteness not as one identity among others but as the very grammar of national belonging. Legal scholar Ian Haney López argues in *White by Law: The Legal*

¹⁹ As Omi and Winant observe, "concepts of ideologies of race... differ according to the sociohistorical conditions" in which they are formed, showing their political and institutional construction. See Michael Omi and Howard Winant, *Racial Formations in the United States*, 3rd ed. (New York: Routledge, 2015), 13.

²⁰ See footnote 17. Scott shows how state projects often distort reality through mechanisms of "legibility and simplification," making populations visible only in ways that serve administrative control.

²¹ For more on how race was instituted as a system of governance, see Dorothy Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century* (New York: The New Press, 2011), 309

²² Naturalization Act of 1790, ch. 3, 1 Stat. 103 (1790).

Construction of Race²³ that racial categories have never been discovered so much as declared, their coherence not assumed but secured through the legitimating force of law.²⁴ It was the very language of the law, and subsequent judicial interpretations, that made whiteness synonymous with citizenship and non-whiteness synonymous with exclusion.²⁵ By limiting naturalization to "free white persons," the act codified a racial logic that shaped American citizenship, exclusion, and identity. This framework not only denied citizenship based on race but also laid the groundwork for enduring associations between whiteness, nationhood, and legal recognition.

What followed was not the simple application of a racial standard, but the court's active participation in shaping what race would come to mean. With no statutory definition of whiteness to rely on, judges were tasked with making race legible through law. This work of racial construction unfolded through a series of naturalization cases in which applicants sought to prove they were "white" and therefore eligible for citizenship. In adjudicating these cases, courts turned to two unstable and often contradictory logics: the first grounded in "common knowledge," or the presumed intuition of the average American regarding who appeared white; the second rooted in "scientific evidence," which drew on anthropological and ethnological theories to define race as biological or ancestral.²⁶ This dual framework—never formally

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²³ Ian Haney López, *White by Law: The Legal Construction of Race*, 25th Anniversary ed. (New York: New York University Press, 2006).

²⁴ The phrase "the force of law" is used here intentionally, drawing from Walter Benjamin's critique in "Critique of Violence," where he distinguishes between law-making and law-preserving violence—both of which, he argues, assert authority not through legitimacy alone, but through force. In this context, law does not simply reflect racial meaning; it imposes it. See Walter Benjamin, "Critique of Violence," in *Reflections: Essays, Aphorisms, Autobiographical Writings*, ed. Peter Demetz, trans. Edmund Jephcott (New York: Harcourt Brace Jovanovich, 1978), 277–300.

²⁵ See footnote 22., 91. "Legal language can allow ideas of race to transcend their historical context through precedent and also can contribute to the construction of race by providing a new vocabulary with which to take note of, stigmatize, and penalize putative racial differences."

²⁶ Ibid., 48. "Among the lower courts in that period, six relied on scientific evidence, while seven others embraced a common-knowledge approach. No court relied on both rationales. Moreover, in every scientific evidence case the petitioner was held to be a 'white person,' while in every case but one that turned on common knowledge the court barred the petitioner from naturalization."

codified, yet consistently invoked—made clear that race in law was not a fact to be discovered but a status to be assigned. *In re Ah Yup*,²⁷ often regarded as the first case to explicitly deny citizenship on racial grounds, marks a critical moment in the legal fabrication of race. The petitioner, a Chinese immigrant, sought naturalization under the presumption that he might qualify as "white"—a term left undefined by law yet treated as foundational to national identity. Faced with this ambiguity, the court did not merely interpret the statute; it produced a racial meaning through a synthesis of "common knowledge" and contemporary racial science. The judge concluded that Ah Yup was not "a white person" under the statute, reasoning that "these words in this country, at least, have undoubtedly acquired a well settled meaning in common popular speech, and they are constantly used in the sense so acquired in the literature of the country, as well as in common parlance." Rather than clarify the meaning of whiteness, the decision reaffirmed it as a standard rooted in cultural familiarity and exclusion—recognizable only in opposition to those deemed outside it.

What made *Ah Yup* important was not just the decision itself, but the approach it set in motion—treating race as something the courts could define, justify, and enforce.²⁹ It established a way of thinking in which racial identity wasn't taken as self-evident, but had to be constructed through exclusion and legal reasoning. This case is worth revisiting not only for its historical role, but because, like all precedent in law, it shaped how future cases would be argued and decided. The reasoning in *Ah Yup*—rooted in public perception, racial science, and cultural familiarity—would go on to influence the cases that followed, especially those involving racial

²⁷ In re Ah Yup, 1 F. Cas. 223 (C.C.D. Cal. 1878) (No. 104), 224.

²⁸ Ibid

²⁹ See footnote 23. López writes, "What we look like, the literal and 'racial' features we in this country exhibit, is to a large extent the product of legal rules and decisions.... On this level, too, law creates races." *White by Law*, 11.

groups on the margins of whiteness. Within this framework, *Dow v. United States*³⁰ emerges as a key moment in the legal history of Middle Eastern and North African identity—where a Syrian Christian immigrant made the case not just for naturalization, but for recognition within the shifting legal meaning of whiteness.

George Dow petitioned for citizenship at a time when the racial status of Middle Easterners was uncertain. Like earlier applicants, Dow faced legal resistance grounded in the claim that Syrians were not "white" within the meaning of U.S. naturalization law.³¹ Yet unlike *Ah Yup*, his case resulted in recognition. In some strands of early 20th-century racial science, Middle Easterners were variably classified under the label 'Caucasian,' often alongside Southern Europeans and South Asians. These classifications, however, were inconsistent and selectively mobilized in legal arguments such as *Dow v. United States*, more to serve political ends than to reflect anthropological consensus. ³² Because whiteness had already been extended to Southern and Eastern Europeans, the court reasoned that certain Middle Easterners—particularly Christians like Dow—could also be granted inclusion.³³

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³⁰ Dow v. United States, 226 F. 145 (4th Cir. 1915).

³¹ Sarah Gualtieri shows how Syrian advocates defending Dow's whiteness relied on racist comparisons, arguing that denying citizenship would place Syrians "no better than blacks [al-zunuj] and Mongolians [al-mughuli]," despite emphasizing shared Christian heritage with white Americans. See Sarah Gualtieri, *Between Arab and White: Race and Ethnicity in the Early Syrian American Diaspora* (Berkeley: University of California Press, 2009), 72.
32 Early racial science—most notably Johann Friedrich Blumenbach, grouped Europeans, North Africans, and "western Asiatics" under the "Caucasian" race—provided a foundational but expansive racial typology. Yet in early 20th-century naturalization cases such as *Ex Parte Shahid* and *Dow v. United States*, courts selectively invoked or outright rejected such classifications. As Ian Haney López notes, Judge Smith dismissed scientific definitions and instead anchored whiteness in the racial common sense of 1790, even responding to claims that denying Syrians whiteness was tantamount to denying the whiteness of Jesus Christ. See Johann Friedrich Blumenbach, *The Anthropological Treatises of Johann Friedrich Blumenbach*, trans. and ed. Thomas Bendyshe (London: Longman, Green, Longman, Roberts, & Green, 1865), 303; Originally published as *Beyträge zur Naturgeschichte* (Göttingen: Dieterich, 1795).

³³ See *In re Najour*, 174 F. 735 (N.D. Ga. 1909) and *United States v. Cartozian*, 6 F.2d 919 (D. Or. 1925), which ruled that Middle Easterners (Armenians) were white under U.S. naturalization law. See also *Ex parte Mohriez*, 66 F. Supp. 35 (D. Mass. 1944), which further extended whiteness to Arabians.

However, this ruling was not based solely on biological classification. The court also considered cultural and religious factors, emphasizing that Syrian Christians were perceived as more assimilable into American society than other non-European groups. ³⁴ By highlighting Dow's Christian background, the decision reinforced the idea that whiteness was not determined only by skin color or ancestry, but also by proximity to dominant social and cultural norms. As Khaled Beydoun explains, the ruling functioned as "a judicial declaration that called for the rescue of Christian minorities in the Arab World at a time when the Ottoman Empire—the primary political manifestation of Islam in 1915—was at war with the European allied powers in World War I."35 In this context, the court's recognition of Dow's whiteness was as much a geopolitical and religious gesture as it was a legal one. The decision granted some Middle Eastern immigrants access to citizenship while continuing to exclude others, particularly those who lacked the religious or cultural markers deemed compatible with American identity, demonstrating that race was not a fixed or neutral category, but one constructed and applied selectively through law. This selective application becomes even more apparent when contrasted with the treatment of other groups who attempted to claim whiteness through scientific reasoning.

Less than a decade later, the Supreme Court reached the opposite conclusion in United States v. Thind,³⁶ denying citizenship to Bhagat Singh Thind, a high-caste Indian Sikh. Thind, like George Dow, grounded his claim in prevailing racial science—arguing that Indians were

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³⁴ Beydoun writes: "In *Ex parte Dow*, Judge Smith wanted to know whether George Dow, a Syrian Christian, was a 'real' Christian. Smith's answer was an emphatic no—the petitioner's Arabic fluency was prima facie evidence of Muslim identity." This shows how the Christian identity was treated as a marker of racial eligibility, demonstrating that religion played a critical role in determining whether MENA immigrants could be classified as white. See Khaled A. Beydoun, *Between Muslim and White: The Legal Construction of Arab American Identity*, 69 *N.Y.U. Annual Survey of American Law* 29 (2013), available at SSRN: https://ssrn.com/abstract=2529506.

³⁵ Ibid.

³⁶ United States v. Thind, 261 U.S. 204, 211 (1923).

classified as "Caucasian" and therefore eligible for citizenship under the same scientific classification that had benefited Dow.³⁷ The Supreme Court, however, rejected this argument outright with Justice George Sutherland ruling that even if Thind was considered Caucasian by anthropologists, he was not white in the "common understanding" of the term as used by the average American.³⁸ The Court made clear that whiteness was not just a scientific or biological classification, but also a social construct—one defined by how white Americans perceived a racial group's assimilability, physical appearance, and cultural background.

Unlike Syrian Christians, Indian immigrants—particularly Sikhs like Thind—were perceived as too culturally and physically distinct from white Americans to be considered part of the white racial category. The Court emphasized popular perception, stating that "the average man knows perfectly well that there are unmistakable and profound differences" between Indians and white Americans.³⁹ While one could argue that complexion alone would have excluded many Indian immigrants from whiteness, the ruling did not hinge on physical appearance or scientific reasoning alone. Instead, it affirmed that legal whiteness was determined by prevailing social attitudes—by whether a group was seen as assimilable, familiar, and culturally proximate.

Thus, if Thind's exclusion reveals the state's investment in whiteness as a socially intelligible and politically expedient category, it also exposes the precarity of Middle Eastern inclusion. The same logic that temporarily allowed for Dow's admission could be—and were—

³⁷ See footnote 32. Blumenbach states, "Thus the Hindoos might be separated as particular sub-varieties from the Caucasian," 304.

³⁸ Justice George Sutherland, delivering the opinion of the Court in *United States v. Thind*, rejected the scientific classification of Thind as Caucasian, stating that racial categories for naturalization should align with the "common understanding" of whiteness. See footnote 36.

³⁹ Ibid.

retracted when convenient. By the time of the Immigration Act of 1924,⁴⁰ this logic had been fully codified. Deeply influenced by eugenicist theories and racial anxieties about preserving an Anglo-Saxon-dominated America, the Act established national origin quotas that enshrined whiteness—not as a universal legal category, but as a selective and hierarchical one.⁴¹ By using the 1890 census as its baseline, the law ensured that immigration levels would reflect a time before the mass arrival of Italians, Jews, Slavs, and other Southern and Eastern Europeans, reinforcing the idea that only certain Europeans were racially desirable.⁴² While earlier court decisions like *Dow v. United States* had at times permitted Middle Eastern immigrants to claim whiteness, the 1924 Act reassigned them to the margins, assigning the entire Arab world fewer than 100 immigration slots annually and incorporating parts of the region into the Asiatic Barred Zone.⁴³ Even as the *Dow* ruling remained on the books, its promise was hollow. Racial status, however nominally granted, no longer guaranteed entry—let alone belonging.

This becomes clear in *In re Ahmed Hassan*,⁴⁴ where an Arab Muslim applicant was denied naturalization despite the precedents set in *Dow*. The court ruled that Hassan did not meet the racial requirement of whiteness—not simply because of phenotype or origin, but because of a

⁴⁰ Immigration Act of 1924, Pub. L. No. 68-139, 43 Stat. 153.

⁴¹ Ibid., The act set quotas based on the 1890 census (Section 11), barred all immigration from the Asiatic Barred Zone (Section 13(c)), and prohibited immigration for those ineligible for naturalization, effectively excluding most Asians (Section 13(a)).

⁴² Lawmakers relied on the work of eugenicists like Madison Grant and Harry Laughlin, who argued that restricting immigration was necessary to protect the racial purity of the United States. Congressional debates and reports explicitly referenced eugenics to justify the exclusion of Southern and Eastern Europeans, as well as nonwhite populations. See *Congressional Record*, 68th Cong., 1st Sess. (1924).

⁴³ National Archives and Records Administration, "Asian American and Pacific Islander Records: Immigration," *National Archives*, https://www.archives.gov/research/aapi/immigration. The Asiatic Barred Zone included "any country not owned by the U.S. adjacent to the continent of Asia."

⁴⁴ In re Ahmed Hassan, 48 F. Supp. 843 (E.D. Mich. 1942).

perceived cultural and religious incompatibility with American identity.⁴⁵ Islam, it seems, exceeded the elastic boundaries of whiteness that Christianity had previously managed to stretch.

Yet the work of racial governance did not end with exclusionary laws like the Immigration Act of 1924. As overtly racist quotas began to wane mid-century, a new mechanism took shape: federal data standardization. In 1964, the creation of the Federal Interagency Committee on Education (FICE), and later the Office of Management and Budget (OMB), marked a shift in how the state would manage racial identity—not by denying legal whiteness, but by codifying it into bureaucratic procedure. These early efforts to standardize racial and ethnic data across federal agencies left the classification of MENA individuals untouched, folding them into the "White" category with no opportunity for distinct recognition. The legal exclusion of earlier decades was thus quietly transformed into administrative invisibility—a shift in form, not in function.

These early classification practices would culminate in the issuance of OMB Directive 15, first issued in 1977 and later revised in 1997.⁴⁶ This directive established the racial and ethnic categories used across federal agencies, including the U.S. Census. According to OMB Directive 15, the government recognized five racial categories—White, Black or African American, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander—and one ethnic category: Hispanic or Latino, separate from race.

⁴⁵ Ibid. "Apart from the dark skin of the Arabs, it is well known that they are a part of the Mohammedan world and that a wide gulf separates their culture from that of the predominantly Christian peoples of Europe. It cannot be expected that as a class they would readily intermarry with our population and be assimilated into our civilization.", https://law.justia.com/cases/federal/district-courts/FSupp/48/843/2391742/.

⁴⁶ Office of Management and Budget, *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*, Federal Register, October 30, 1997. Available at: https://www.whitehouse.gov/wp-content/uploads/2017/11/Revisions-to-the-Standards-for-the-Classification-of-Federal-Data-on-Race-and-Ethnicity-October 30-1997.pdf.

The inclusion of an ethnicity⁴⁷ section in Directive 15 was primarily designed to capture the unique social, political, and cultural experiences of certain populations that did not fit neatly into racial categories.⁴⁸ The Hispanic or Latino designation was introduced as an ethnic category because individuals of Hispanic origin can be of any race but share common cultural and linguistic ties. This distinction allowed for better tracking of disparities in areas such as civil rights enforcement, healthcare access, and employment while acknowledging the racial diversity within Hispanic communities.⁴⁹ By contrast, the MENA population, despite also sharing cultural, linguistic, and regional commonalities, was not granted similar recognition, as the government historically classified them as White in legal contexts.

The decision to classify MENA populations as White stemmed from a combination of historical, political, and logistical factors. When Directive 15 was created, race was largely understood through a social and political lens tied to civil rights enforcement, with federal racial categories designed to track and address disparities.⁵⁰ One of the reasons the OMB did not add a separate MENA category in 1997 was the concern over the cost of data collection and analysis. As stated in congressional discussions:

The cost of collecting information about persons of Arab or Middle Eastern descent from the decennial census is not known. Components of the cost are the cost of adding a

⁴⁷ In the context of U.S. federal classification systems, "race" is typically used to refer to groups defined by perceived physical characteristics and historical power dynamics (e.g., Black, White, Asian), whereas "ethnicity" refers to shared cultural, linguistic, or national origins. However, the distinction is often blurred in practice, and both categories are socially constructed rather than biologically grounded.

⁴⁸ See footnote 46. "The categories represent a social-political construct designed for collecting data on the race and ethnicity of broad population groups in this country, and are not anthropologically or scientifically based."

⁴⁹ Ibid. "Development of the data standards stemmed in large measure from new responsibilities to enforce civil rights laws. Data were needed to monitor equal access in housing, education, employment, and other areas, for populations that historically had experienced discrimination and differential treatment because of their race or ethnicity."

⁵⁰ Ibid. "The standards have been developed to provide a common language for uniformity and comparability in the collection and use of data on race and ethnicity by Federal agencies."

specific category to the form itself and then the cost of analyzing the resultant data to determine its quality and usefulness. The cost of tabulations of data would incrementally increase with the addition of a new category. As Table 5.2 indicates, the 1990 census reports did tabulate Arab or Middle Easterner, but under two different definitions.⁵¹

While the primary justification emphasized cost, federal agencies also raised concerns about the technical quality and consistency of data that might result from adding a MENA category. A 2001 CDC report on the implementation of new racial standards acknowledged the need for "good technical information about the quality and the reliability of the data," especially in emerging categories where definitions and public familiarity might be less stable. ⁵² Although explicit concerns about a MENA category's validity were not formally documented at the time, the absence of a standard definition and potential inconsistencies in self-identification likely contributed to institutional hesitancy.

Yet, many of these concerns—such as definitional ambiguity⁵³ and self-identification inconsistencies⁵⁴—were also present when categories like "Hispanic" or "Asian American" were introduced, yet solutions were found over time.⁵⁵ The question, then, is not whether these

⁵¹ See footnote 6.

⁵² Durch JS, Madans JH. Methodological issues for vital rates and population estimates: The 1997 OMB standards for data on race and ethnicity. National Center for Health Statistics. Vital Health Stat 4(31). 2001. https://www.cdc.gov/nchs/data/series/sr 04/sr04 031.pdf?utm

⁵³ The U.S. Census Bureau defines "Hispanic or Latino" as an ethnicity, not a race, encompassing individuals of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. U.S. Census Bureau, *About Hispanic Population and its Origin*, https://www.census.gov/topics/population/hispanic-origin/about.html.

⁵⁴ The Pew Research Center reported that many Latinos do not identify with the existing U.S. racial categories, leading a significant number to select "Some Other Race" on census forms. Pew Research Center, *The Many Dimensions of Hispanic Racial Identity*, https://www.pewresearch.org/social-trends/2015/06/11/chapter-7-the-many-dimensions-of-hispanic-racial-identity/.

⁵⁵ See footnote 6. "There are no clear, unambiguous, objective, generally agreed-upon definitions of the terms, 'race' and 'ethnicity.' Cognitive research shows that respondents are not always clear on the differences between race and ethnicity. There are differences in terminology, group boundaries, attributes, and dimensions of race and

concerns exist, but which ones ought to be prioritized in light of the health disparities faced by MENA populations. Concerns about cost or initial data inconsistency, while valid, should not outweigh the ethical imperative to document and respond to unmet health needs. The inclusion of a MENA category should be seen not as a premature fix but as a necessary intervention in a system that continues to render certain populations invisible.

The post-9/11 era marked a drastic shift in the legal and social treatment of MENA communities. Laws like the USA PATRIOT Act⁵⁶ expanded surveillance and law enforcement powers,⁵⁷ disproportionately targeting Middle Eastern, South Asian, and Muslim populations regardless of citizenship.⁵⁸ Programs like the National Security Entry-Exit Registration System (NSEERS)⁵⁹ required men from 25 Muslim-majority countries to register with authorities, resulting in mass detentions and deportations without yielding terrorism-related convictions, exposing its role as a tool for racial profiling rather than legitimate national security.⁶⁰ Simultaneously, hate crimes and discrimination surged: anti-Muslim hate crimes spiked 1,600% in 2001, and the trend continued for years.⁶¹ In the weeks following 9/11, individuals like Balbir Singh Sodhi, a Sikh man mistaken for a Muslim, and Waqar Hasan, a Pakistani immigrant, were

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ethnicity. Historically, ethnic communities have absorbed other groups through conquest, the expansion of national boundaries, and acculturation."

⁵⁶ USA PATRIOT Act, Pub. L. No. 107-56, 115 Stat. 272

⁵⁷ See Louise A. Cainkar, *Homeland Insecurity: The Arab American and Muslim American Experience After 9/11* (Russell Sage Foundation, 2009), which details the surveillance, detention, and profiling of MENA and Muslim communities post-9/11.

⁵⁸ American Civil Liberties Union (ACLU), *Unleashed and Unaccountable: The FBI's Unchecked Abuse of Authority* (2013), https://www.aclu.org/documents/unleashed-and-unaccountable-fbis-unchecked-abuse-authority.

⁵⁹ U.S. Department of Homeland Security. *Removing Designated Countries from the National Security Entry-Exit Registration System (NSEERS)*. Federal Register 76, no. 82 (April 28, 2011): 23730–23731. https://www.federalregister.gov/documents/2011/04/28/2011-10305/removing-designated-countries-from-the-national-security-entry-exit-registration-system-nseers.

⁶⁰ Center for Immigrants' Rights, Pennsylvania State University's Dickinson School of Law, *The NSEERS Effect: A Decade of Racial Profiling, Fear, and Secrecy*, 2012, https://pennstatelaw.psu.edu/file/clinics/NSEERS_report.pdf. ⁶¹ Federal Bureau of Investigation, Uniform Crime Reporting Program, 2001, https://ucr.fbi.gov/hate-crime/2001/hatecrime01.pdf.

murdered in hate crimes.⁶² At airports⁶³ and workplaces,⁶⁴ profiling and exclusion became routine, further marginalizing MENA individuals. Legal challenges cited constitutional violations, yet many measures endured, reinforcing alienation.

More recently, Executive Order 1415—Protecting the United States from Foreign

Terrorists and Other National Security and Public Safety Threats (January 2025)⁶⁵—has

intensified the vetting of immigrants and visitors from regions identified as national security

risks. While the order does not name specific countries, its broad language and sweeping

mandates echo earlier frameworks that have been criticized as potentially xenophobic and

arbitrary. Though a full analysis of its political calculus lies beyond the scope of this thesis, its

invocation here signals that the legal classification and treatment of MENA populations remains

unsettled, shaped less by principled legal reasoning than by fluctuating security imperatives.

This section has shown that the legal classification of MENA populations has never rested on fixed definitions, but rather on shifting imperatives of governance. Rather, it has been shaped by a shifting matrix of judicial interpretation, legislative exclusion, bureaucratic convenience, and national security anxiety. What appears as inconsistency is, in fact, a consistent strategy—one that withholds stable recognition to preserve state flexibility. The next section

⁶² Harmeet Kaur, "A Sikh man's murder at a gas station revealed another tragedy of 9/11," CNN, September 11, 2021, https://www.cnn.com/interactive/2021/09/us/balbir-singh-sodhi-9-11-cec/.

⁶³ Public opinion polls have indicated varying levels of support for racial profiling at airports among the general American population. A 2004 Gallup poll found that 45% of respondents supported such measures at airport security checkpoints, while a 2010 CBS News poll reported a decrease, with 37% in favor. See Saher Selod, *Scholars Strategy Network*, 2014, "Targeting Muslim Americans in the Name of National Security," available at https://scholars.org/contribution/targeting-muslim-americans-name-national-security.

⁶⁴ Stan Malos, "Post-9/11 Backlash in the Workplace: Employer Liability for Discrimination against Arab- and Muslim-Americans Based on Religion or National Origin," *Employee Responsibilities and Rights Journal* 21, no. 4 (2009): 297–310. https://doi.org/10.1007/s10672-009-9132-4.

⁶⁵ White House. *Protecting the United States from Foreign Terrorists and Other National Security and Public Safety Threats*. Executive Order 14161, January 2025. https://www.whitehouse.gov/presidential-actions/2025/01/protecting-the-united-states-from-foreign-terrorists-and-othernational-security-and-public-safety-threats/.

turns to that function directly, examining how racial categories operate as practices of governance—structured and deployed by institutions to manage populations.

B. Racial Categories as Governance

The previous section showed how legal and bureaucratic practices render MENA populations racially legible—not through stable definitions, but through shifting, historically contingent decisions. What emerges is a pattern: the law does not recognize race; it constructs it.⁶⁶ This section turns to the political work that racial classification performs. If law helps produce race, then classification must be understood not as a reflection of social reality but as a strategic practice aligned with political, economic, and security interests.⁶⁷

To understand this logic, I draw briefly on Michel Foucault—not to offer a full account of biopower, but to clarify what is at stake when we treat racial classification as a mechanism of governance.⁶⁸ Biopower describes the shift from sovereign power over death to modern power over life: the regulation of populations, normalization of behavior, and management of health. Within this framework, classification is not passive recognition but active intervention. It shapes which lives are knowable, improvable, or disposable.⁶⁹ This insight reframes the work of classification in the chapters that follow. It is not merely a precondition for surveillance,

⁶⁶ See footnote 23. López argues that law constructs race by ascribing meaning to physical features and embedding those meanings in material conditions: "Law creates differences in physical appearance... and translates ideas about race into the material societal conditions that confirm and entrench those ideas," (White by Law, 10).

⁶⁷ Kimberlé Crenshaw argues that racism operates not only through exclusion but through ideological dominance—what she calls its *hegemonic function*. Legal frameworks that claim neutrality often legitimize racial hierarchy. Citing Crenshaw acknowledges the intellectual lineage of this argument and situates it within a broader tradition of Black critical thought. See "Race, Reform, and Retrenchment," *Harvard Law Review* 101, no. 7 (1988): 1331–87. https://harvardlawreview.org/print/vol-133/race-reform-and-retrenchment/.

⁶⁸ See Michel Foucault, *Society Must Be Defended: Lectures at the Collège de France, 1975–76*, ed. Mauro Bertani and Alessandro Fontana, trans. David Macey (New York: Picador, 2003).

⁶⁹ While beyond the scope of this thesis, Achille Mbembe's concept of *necropolitics* extends Foucault's biopower by theorizing how modern states wield the power to expose certain populations to death, abandonment, or social irrelevance. See Achille Mbembe, *Necropolitics*, trans. Steven Corcoran (Durham, NC: Duke University Press, 2019).

statistical analysis, or funding allocation—it is the very technique that makes such interventions possible. Biopower helps us see that the harms of misclassification or non-recognition are not incidental; they are embedded in the very logic of a system that governs through what it chooses to see.

What follows in this section are three interrelated manifestations of this logic. First, how the state surveils without naming—rendering MENA communities governable through suspicion even in the absence of formal classification. Second, how this logic preserves the statistical dominance of whiteness by selectively maintaining MENA populations within the "White" category. And third, how it withholds political recognition and redistributive resources from communities not granted categorical visibility. In each case, classification functions less as a passive record of identity and more as an active tool of governance. It is in this sense that the biopolitical stakes of classification become most apparent—not in how categories describe people, but in how they manage life itself.

a. Surveillance

Of the many political functions racial classification serves, surveillance is among the most direct. It operationalizes classification by enabling the state to monitor and manage populations marked as risky or deviant. The practice of monitoring Arab American political activity in the United States gained coherence after the 1967 Arab–Israeli War, which marked a shift in both U.S. foreign policy in the Middle East and the domestic visibility of Arab American communities.⁷⁰ Expressions of political solidarity with Palestinians, especially in student

⁷⁰ The 1967 war "galvanized the Arab American scholars and professionals who became active in the AAUG" and "intensified the politicization of many Arabs and Arab Americans studying at American universities." See Pamela E.

organizations, drew increased scrutiny from federal authorities. These activities, viewed through a Cold War security lens, rendered transnational affiliations suspect.⁷¹

This logic materialized⁷² in 1972 with Operation Boulder, a Nixon-era initiative following the Munich Olympic attacks.⁷³ Initially targeting visa applicants from Arab-majority countries, it quickly broadened to surveil Arab American citizens and community organizations.⁷⁴ Federal agencies collected data, shared intelligence, and monitored political activity, with an estimated 150,000 individuals affected.⁷⁵ As Pamela Pennock notes, the program aimed less to uncover security threats than to contain Arab political expression, treating Arab identity itself as suspicious.⁷⁶ Although Operation Boulder uncovered no cases of terrorism or espionage, it helped solidify a framework in which Arab political expression was treated as inherently risky.⁷⁷

Pennock, The Rise of the Arab American Left: Activists, Allies, and Their Fight against Imperialism and Racism, 1960s-1980s (Chapel Hill: University of North Carolina Press, 2017), 47.

⁷¹ "INS, in conjunction with the FBI, investigated Arabs already in the United States on student and visitor visas. In a separate but related tactic, the FBI targeted politically active Arab Americans, including American citizens, for surveillance and investigation." See Pamela E. Pennock, "From 1967 to Operation Boulder: The Erosion of Arab Americans' Civil Liberties in the 1970s," *Arab Studies Quarterly* 40, no. 1 (Pluto Journals, 2018): 42. https://www.jstor.org/stable/10.13169/arabstudquar.40.1.0041.

⁷² See U.S. Department of State. *Foreign Relations of the United States, 1969–1976, Volume E–3, Documents on Global Issues, 1973–1976.* Document 214, "Memorandum From the Special Assistant to the Secretary of State and Coordinator for Combating Terrorism (Hoffacker) to the Deputy Undersecretary for Management (Brown)," April 23, 1974. Washington, DC: Government Printing Office. https://history.state.gov/historicaldocuments/frus1969-76ve03/d214.

⁷³ Initiated under the Nixon administration following the 1972 Munich Olympic attacks—where eleven Israeli athletes were taken hostage and killed by the Palestinian group Black September—the program was designed to screen visa applicants from Arab-majority countries more intensively.

⁷⁴ See footnote 71., 48. Despite Operation Boulder's end in 1975, surveillance of Arab American activists continued into the 1980s, with groups like OAS and ADC reporting FBI harassment despite no charges.

⁷⁵ Ibid.

⁷⁶ Ibid., 45.

⁷⁷ Ibid., 43.

The 1996 Antiterrorism and Effective Death Penalty Act (AEDPA)⁷⁸ of 1996 further institutionalized this trend.⁷⁹ Though passed in response to domestic terrorism, its foreign terrorist organization (FTO) provisions primarily affected Arab and Muslim groups.⁸⁰ Of the initial 28 designated FTOs, over half were Arab or Muslim organizations, reflecting Middle East-centered scrutiny.⁸¹ These designations,⁸² implemented with minimal oversight, allowed the use of secret evidence and funding restrictions that undermined civic life and legal protections for these communities.⁸³

After 9/11, surveillance expanded further. The USA PATRIOT Act and NSEERS entrenched racialized monitoring in federal policy. Beyond these high-profile measures, programs like the FBI's Countering Violent Extremism (CVE) initiative blurred community engagement with intelligence gathering.⁸⁴ In practice, CVE enlisted educators, religious leaders, and mental health professionals to report signs of supposed "radicalization," often based on vague criteria.⁸⁵ Informants were placed in mosques and civic spaces, sometimes goading targets

⁷⁸ Antiterrorism and Effective Death Penalty Act of 1996, Pub. L. No. 104–132, §§ 302–303, 110 Stat. 1214, 1248–50 (1996); see also Immigration and Nationality Act § 219, 8 U.S.C. § 1189; and 18 U.S.C. § 2339B.

⁷⁹ While this thesis centers on groups from the MENA region, I include Muslim communities not to conflate religious and ethnic identities, but to acknowledge how U.S. surveillance practices have historically treated them as overlapping or indistinguishable. This inclusion reflects both the cultural entanglements within these communities and the state's tendency, whether through misunderstanding or design, to treat Arabness and Muslimness as interchangeable markers of risk.

⁸⁰ See Michael J. Whidden, "Unequal Justice: Arabs in America and United States Antiterrorism Legislation," *Fordham Law Review* 69, no. 6 (2001): 2825–2861, https://ir.lawnet.fordham.edu/flr/vol69/iss6/15/.

⁸¹ Ibid., 2828.

⁸² Ibid., 2883.

⁸³ Ibid., 2827. "Arabs in America have been particularly burdened by AEDPA. Of the approximately two dozen immigrants currently detained on secret evidence, almost all are either Arab or Muslim."

⁸⁴ See Faiza Patel and Meghan Koushik, *Countering Violent Extremism* (New York: Brennan Center for Justice, 2017), https://www.jstor.org/stable/resrep28416.1, for a discussion on how CVE initiatives disproportionately focused on Muslim communities under the guise of neutral community engagement.

⁸⁵ See *Brief for Asian Americans Advancing Justice—Asian Law Caucus et al. as Amici Curiae in Support of Respondents*, *FBI v. Fazaga*, No. 20-828, U.S. Supreme Court, filed Sept. 28, 2021, at 16–22, https://www.supremecourt.gov/DocketPDF/20/20-828/193953/20210928150009785 41482%20pdf%20Alam.pdf, for a discussion of FBI's suspicionless surveillance of Muslims, including "mosque outreach" programs in the Bay Area.

toward incriminating behavior.⁸⁶ The No-Fly List and Terrorist Screening Database denied travel rights to many without due process, disproportionately impacting Muslims and Arabs.⁸⁷

Surveillance thus emerges as a key site where the contradictions of racial classification take shape. Arab and Muslim communities have been rendered visible to the state not through recognition but suspicion. The absence of a distinct racial category has not protected these populations; it has enabled their scrutiny. Ambiguous classification allows the state to racialize through other means—what Foucault might call a regulatory gaze⁸⁸—that attaches risk without formal designation. Racialization here does not follow from legal categories; it precedes and produces them.

b. Statistical Dominance of Whiteness

If the previous section traced how Arab and Muslim communities have been rendered vulnerable through practices of surveillance, this section turns to a different, though no less consequential, mechanism of state power: the selective preservation of statistical whiteness. The federal government does not apply racial classification consistently or transparently. Rather, it racializes strategically—intensifying visibility when it aligns with national security imperatives and withholding formal recognition when it threatens existing political and demographic arrangements.

⁸⁶ See Jesse J. Norris, "Accounting for the (Almost Complete) Failure of the Entrapment Defense in Post-9/11 US Terrorism Cases," Law & Social Inquiry 45, no. 1 (2020): 194–225, https://doi.org/10.1017/lsi.2019.61.

⁸⁷ Matthew Barakat, "Lawsuit by Islamic rights group says US terror watchlist woes continue even after names are removed," *Associated Press*, September 18, 2023, https://apnews.com/article/terror-watchlist-lawsuit-jersey-mayor-47765ad91468d7e04f0e7155d3baf134.

⁸⁸ See footnote 18. The phrase "regulatory gaze" draws conceptually from theories of state surveillance and institutional power, particularly those developed by Michel Foucault.

The size of the "White" population has long shaped political power in the U.S., influencing redistricting, voting power, and racial discourse.⁸⁹ A decline in those counted as White could shift electoral demographics and resource distribution. In the 1997 OMB analysis regarding whether the MENA category should be included, it was outlined and documented that:

The addition of a racial category in which persons of Arab or Middle Eastern descent might respond could reduce the total number of Whites counted in the next census. If an ethnic category were added, rather than a racial category, there would be no reduction in the numbers of any racial category. Before such an addition could be made, however, there would have to be agreement on how the new category would be defined. As the public comments have indicated, this is not an easy task.⁹⁰

The difficulty in defining this category—and the political implications of doing so—partly explains why the federal government has stalled on this decision for so long.

If Arabs, Middle Easterners, and North Africans were allowed to identify separately, this could shift the balance, diluting the perceived dominance of the White population and disrupting the status quo. The state's resistance to defining a new racial category is thus inseparable from the broader effort to maintain existing power relations.⁹¹

⁸⁹ Data from surveys conducted by the Census Bureau "guide distribution of funds for federal financial assistance programs by defining recipient eligibility, defining variables in fund allocation formulas, and establishing program applicant selection criteria." See Taylor R. Knoedl, *The U.S. Census Bureau: An Overview*, Congressional Research Service, R47847 (November 22, 2023), https://crsreports.congress.gov/product/pdf/R/R47847.

⁹⁰ Office of Management and Budget. "Directive No. 15: Race and Ethnic Standards for Federal Statistics and Administrative Reporting." The White House, 2000, https://obamawhitehouse.archives.gov/omb/fedreg directive 15/?.

⁹¹ See Ann Morning, "Ethnic Classification in Global Perspective: A Cross-National Survey of the 2000 Census Round," *Population Research and Policy Review* 27, no. 2 (2008): 239–272, https://doi.org/10.1007/s11113-007-9062-5 for more on how the U.S. approaches race and ethnic enumeration.

What's at stake is not just demographic accuracy, but the preservation of racialized power. 92 As this thesis has begun to show, racial classification operates less as a neutral descriptor than as a regulatory practice. The selective inclusion of MENA populations within the "White" category works to preserve the statistical dominance of whiteness—a dominance that underpins both representational authority and access to federal resources. 93 Census data inform everything from redistricting and political representation to funding for public health, education, and social services.

This section, then, bridges the logics of surveillance and resource distribution. It demonstrates how classification—by sustaining the numerical strength of whiteness—also reinforces the legitimacy of racial hierarchies within law and public policy. ⁹⁴ It anticipates the next section, which will examine how the denial of political recognition and material resources further entrenches the precarity of MENA communities, not as an aberration but as a logical consequence of how race is wielded as a political instrument.

c. Denying Political and Resource Funding

If the previous sections traced how Arab and Muslim communities have been subject to state surveillance and incorporated into the statistical logic of whiteness, this section turns to a third and equally consequential expression of racial classification as a political instrument: the distribution of institutional resources. To be counted is not only to be known, but to be positioned within systems of allocation—of funding, care, recognition. What has been shown

⁹² As Melissa Nobles writes, "The Census Bureau has escaped inquiry both as a state institution that determines the benefits and penalties of racial memberships through the data it collects and as a place where racial categories themselves are constructed." Melissa Nobles, *Shades of Citizenship: Race and the Census in Modern Politics* (Stanford, CA: Stanford University Press, 2000), 17.

⁹⁴ See footnote 23.

thus far is that classification does not follow a stable logic of identity, but rather a shifting calculus of risk and power. Here, I turn to what becomes available—or foreclosed—through the state's refusal to recognize MENA populations as a distinct racial group.

Federal classification is a technology that structures access to research, policy attention, and material support. Public health initiatives, civil rights enforcement, and funding formulas rely on data shaped by these categories. To be excluded from them is to be absent from the very metrics by which inequality is identified and addressed. Thus, this section does not merely ask what classification reveals, but what it enables—and what its absence denies.

Federal funding and public health priorities rely heavily on racial and ethnic data, and the absence of a MENA category results in these communities being excluded from health interventions and resources designed to address racial disparities. Federal health agencies, including the Centers for Disease Control and Prevention (CDC)⁹⁵ and the National Institutes of Health (NIH),⁹⁶ allocate resources based on health disparity data categorized by race and ethnicity. The relationship between classification and funding is codified in legislation. The Minority Health and Health Disparities Research and Education Act of 2000 (Public Law 106-525) established the National Institute on Minority Health and Health Disparities (NIMHD) to fund research on health disparities among federally recognized racial and ethnic groups.⁹⁷ While

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⁹⁵ T.L. Armstead, K. Castelin, C.P. Cairns, et al., "Effects of Investments From the Centers for Disease Control and Prevention's COVID-19 Health Disparities Grant on Health Departments' Capacity to Address Public Health Emergencies," *Public Health Reports* (2025): https://doi.org/10.1177/00333549241310409.

⁹⁶ The NIH Common Fund committed approximately \$24 million total in FY 2021 for the Transformative Research to Address Health Disparities and Advance Health Equity funding opportunity. See NIH Common Fund, *Transformative Research to Address Health Disparities and Advance Health Equity* (RFA-RM-21-021), accessed via NIH Grants & Funding, https://grants.nih.gov/grants/guide/rfa-files/RFA-RM-21-021.html

⁹⁷ In Fiscal Year 2023, NIMHD allocated \$525 million, including \$56 million for chronic disease programs targeting affected groups. NIH also issues funding opportunities requiring projects to address health disparities. National Institute on Minority Health and Health Disparities. Funding strategy. Retrieved from https://www.nimhd.nih.gov/funding/nimhd-funding/funding-strategy.html

the NIMHD was created to address minority health disparities, its funding and research efforts have historically been limited to groups explicitly recognized by federal data collection systems. The CDC's Office of Minority Health and Health Equity (OMHHE) compiles national health disparities reports that guide federal health initiatives like *Healthy People 2030*. Currently, the CDC's health disparities reports do not specifically include data on Arab or MENA populations. MENA populations.

This absence from federal health data has tangible consequences—not only in long-term health planning, but also in emergency responses. A 2023 report from the U.S. Government Accountability Office (GAO) confirms that out of the \$75 billion allocated to the Department of Health and Human Services (HHS) during the COVID-19 pandemic, \$29 billion was explicitly designated for programs serving "communities disproportionately affected by COVID-19," with an additional \$33 billion allocated with guidance to prioritize those same populations. The report notes that these designations were heavily based on data from the U.S. Census Bureau, including race and ethnicity data, which shaped how communities were identified and prioritized. MENA populations were not recognized as a priority group and were effectively excluded from receiving targeted federal aid during the crisis.

⁹⁸ NIMHD. "Minority Health and Health Disparities Research Framework." National Institute on Minority Health and Health Disparities, accessed March 3, 2025. https://www.nimhd.nih.gov/about/overview/research-framework.html. The NIMHD recognizes the following populations as experiencing health disparities: Black or African American, Hispanic or Latino, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander, and individuals from disadvantaged socioeconomic backgrounds.

⁹⁹ Centers for Disease Control and Prevention. "Selected OHE Publications." October 18, 2024. https://www.cdc.gov/minority-health/about/reports-and-initiatives.html.

¹⁰⁰ See footnote 6.

¹⁰¹ United States Government Accountability Office, *COVID-19: HHS Funds Allocated to Support Disproportionately Affected Communities*, GAO-23-105500 (Washington, D.C.: January 2023), https://www.gao.gov/assets/gao-23-105500.pdf.

¹⁰² Ibid., 10.

States receive crisis funds—such as those from CDC testing and vaccination grants—to distribute based on community-level vulnerability, often calculated using the Census Bureau's Social Vulnerability Index (SVI). While the SVI includes factors like race, ethnicity, income, and housing, it lacks a distinct MENA category. As a result, neighborhoods with significant Arab American populations may have been underrepresented in vulnerability assessments and potentially overlooked during resource allocation, given the absence of a distinct MENA category in the SVI. A 2023 GAO report confirms that Washington officials relied on race and ethnicity data from the Census Bureau, along with the Community Resilience Estimates and input from community partners, to direct federal COVID-19 relief funding. The absence of MENA-specific data in these indices reveals how federal racial classification not only shapes long-term health equity frameworks but also has immediate material consequences during times of crisis.

The effects of racial misclassification extend beyond broad public health planning—they also shape access to targeted health services and disease-specific federal programs. Programs like the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provide low-income and minority women with access to cancer screenings. Again, because MENA populations are classified as white, they are not explicitly included as a high-risk group despite research indicating higher rates of thyroid cancer and certain gastrointestinal cancers in

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¹⁰³ Centers for Disease Control and Prevention, *Social Vulnerability Index (SVI)* (Place & Health, July 22, 2024), https://www.atsdr.cdc.gov/place-health/php/svi/index.html. The SVI includes the following race/ethnicity variables: Hispanic or Latino (of any race); Black or African American, Not Hispanic or Latino; Asian, Not Hispanic or Latino; American Indian or Alaska Native, Not Hispanic or Latino; Native Hawaiian or Pacific Islander, Not Hispanic or Latino; Two or More Races, Not Hispanic or Latino; and Other Races, Not Hispanic or Latino. Notably, no distinct MENA category is listed.

¹⁰⁴ See footnote 101, Table 6.

¹⁰⁵ Centers for Disease Control and Prevention. "National Breast and Cervical Cancer Early Detection Program (NBCCEDP)." Last reviewed December 19, 2024. https://www.cdc.gov/breast-cervical-cancer-screening/about/screenings.html#:~:text=What%20to%20know,where%20to%20get%20screened%2C%20contact:.

MENA individuals—a trend that will be discussed in greater detail in Chapter 2, Section B. This exclusion results in lower screening rates and delayed diagnoses.

Mental health services are similarly affected. Federal initiatives addressing mental health disparities—such as the Substance Abuse and Mental Health Services Administration (SAMHSA) Minority Fellowship Program—prioritize groups that are formally recognized in federal racial and ethnic classifications. ¹⁰⁶As a result, MENA individuals, despite experiencing high rates of anxiety and depression—particularly in the post-9/11 context—are not formally included in these efforts. This exclusion contributes to a significant lack of culturally competent ¹⁰⁷ mental health services for MENA communities, a disparity that will be examined further in Chapter 2, Section B.

The consequences of MENA misclassification extend beyond healthcare delivery into the pipeline programs that shape who enters the medical and public health workforce. Federal diversity initiatives, such as the Health Resources and Services Administration's (HRSA) Scholarships for Disadvantaged Students (SDS) program, explicitly prioritize applicants from underrepresented racial and ethnic backgrounds. Similarly, the National Institutes of Health (NIH) offers Diversity Supplements to support the training and mentorship of individuals from federally recognized minority groups in biomedical research. Students who identify as Arab,

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¹⁰⁶ The recognized minority groups in SAMHSA's data taxonomy include Black or African American, Asian, American Indian and Alaska Native, Hispanic or Latino, and Native Hawaiian and Other Pacific Islander. Substance Abuse and Mental Health Services Administration. "Race/Ethnicity Data Taxonomy." https://www.samhsa.gov/data/taxonomy/term/260.

¹⁰⁷ By "culturally competent care," I refer not to a fixed mastery of cultural knowledge, but to an approach that recognizes the social, historical, and political contexts shaping patients' experiences.

¹⁰⁸ Health Resources and Services Administration (HRSA), Scholarships for Disadvantaged Students (SDS) Program Frequently Asked Questions, U.S. Department of Health and Human Services, https://bhw.hrsa.gov/funding/apply-grant/faq-scholarships-disadvantaged-students. The SDS program defines disadvantaged backgrounds to include individuals from the following federally recognized racial and ethnic groups: American Indian or Alaska Native, Black or African American, Native Hawaiian or Other Pacific Islander, and Hispanic (of any race). MENA is not listed.

Middle Eastern, or North African are often ineligible for these forms of support—unless they can demonstrate affiliation with another recognized minority group.¹⁰⁹ This exclusion perpetuates a structural gap in representation, limiting the inclusion of MENA perspectives in medicine, research, and policymaking. In this way, the denial of racial recognition constrains not only community health outcomes, but also who is empowered to shape the future of healthcare itself.

Additionally, Federally Qualified Health Centers (FQHCs), which receive funding through the HRSA, ¹¹⁰ play a critical role in providing care to underserved communities. As part of their funding requirements, FQHCs must submit patient demographic data through the Uniform Data System (UDS), including statistics on race and ethnicity. However, the UDS does not include a distinct category for MENA populations. ¹¹¹ As a result, clinics serving Arab American neighborhoods are unable to accurately document the specific needs of their communities.

What I have traced so far is not simply the exclusion of MENA populations from state recognition, but the logic that makes that exclusion appear natural, justified, or procedurally sound. From surveillance to the statistical preservation of whiteness to the withholding of redistributive resources, each manifestation reveals how racial classification operates not as a mirror of social identity but as a mechanism for managing populations—designating whose lives

¹⁰⁹ NIH Funding Opportunity (e.g., PA-20-222, NOT-OD-20-031) states eligible racial and ethnic groups are those recognized by the NSF as underrepresented: "Blacks or African Americans, Hispanics or Latinos, American Indians or Alaska Natives, Native Hawaiians and other Pacific Islanders" explicitly citing the Office of Management and Budget (OMB) classifications. https://grants.nih.gov/grants/guide/pa-files/pa-20-222.html?utm.

¹¹⁰ Health Resources and Services Administration (HRSA), *UDS: Uniform Data System*, https://data.hrsa.gov/tools/data-reporting/program-data.

¹¹¹ UDS: Uniform Data System, revised October 2019, 1-4, https://bphcdata.net/docs/table 3b.pdf.

warrant investment and whose remain administratively illegible. 112 Building on the historical foundations of MENA misclassification, this chapter has shown how race functions as a political instrument—activated through the dual forces of [in]visibility. Yet to fully understand how this logic endures, I will now turn to the machinery that sustains it: bureaucracy. For MENA communities, the challenge has not simply been making themselves visible to the state, but doing so in a system that only recognizes what it has already decided to see. The next section examines how bureaucratic design reinforces that constraint—how the mechanisms that claim to sort, count, and include are the very ones that obscure, defer, and exclude. In this, we begin to see invisibility not as a lack of data, but as a deeply structured outcome.

C. The Role of Bureaucracy in Structuring Invisibility

If classification renders some communities legible to the state, bureaucracy determines what is done with that legibility—or its absence. This section turns to the mechanisms through which institutional structures, policies, and reporting protocols perpetuate the invisibility of MENA populations. What's at issue is not a singular act of omission, but a self-reinforcing cycle: the lack of formal recognition leads to insufficient data; insufficient data is then used to justify exclusion from funding, research, and intervention, and this exclusion further obscures the need for recognition. Bureaucratic systems, from the Census Bureau to public health data infrastructures, convert racial categories into actionable metrics—but only for those whom the system has been designed to see. This section interrogates how the machinery of governance

¹¹² Stuart Hall argues that race is not a biological essence but a shifting system of representation—a "floating signifier" whose meaning is constructed through historical and institutional processes. See *Stuart Hall: Race, The Floating Signifier*, Directed by Sut Jhally. Northamotion, MA: Media Education Foundation, 1996.

¹¹³ As Geoffrey Bowker and Susan Leigh Star argue, "This mutual process of constructing and shaping differences through classification systems is crucial in anyone's conceptualization of reality; it is the core of much taxonomic anthropology." See *Sorting Things Out: Classification and Its Consequences* (Cambridge: The MIT Press, 1999), 230.

translates classification into material and institutional consequences—such as gaps, misallocated resources, and lack of targeted interventions— and how bureaucratic inertia ensures that invisibility is both the reason for, and the result of, being excluded from systems of care.

MENA health remains trapped in a cycle where lack of data justifies exclusion, and exclusion ensures the lack of data. While the OMB has acknowledged the limitations of current data collection practices, it has repeatedly declined to establish a MENA category, citing the need for further research. As stated by the OMB:

While OMB accepted the Interagency's Committee recommendation not to create a new category for this population group, OMB believes that further research should be done to determine the best way to improve data on this population group. Meanwhile, the writeins to the ancestry question on the decennial census long form will continue to provide information on the number of individuals who identify their heritage as Arab or Middle Easterner.¹¹⁴

This statement illustrates a logic of deferred action that sustains invisibility. By rejecting the formal recognition while simultaneously acknowledging the need for better data, the OMB preserves the status quo. Its reliance on write-in ancestry data—rather than a direct racial or ethnic classification—means that the inclusion of MENA populations remains inconsistent and analytically unreliable, reinforcing their invisibility in health research and policy.

Additionally, the OMB and the Census Bureau have repeatedly delayed recognizing MENA populations as a distinct category in federal data collection. Instead of addressing the issue directly, these agencies have continuously deferred action under the justification that more

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¹¹⁴ See footnote 46.

research is needed. A major opportunity arose in 2015 when the Census Bureau conducted research under the Obama administration on the inclusion of a MENA category for the 2020 Census. The research found that many MENA individuals did not identify as "White" and that adding a MENA category would improve data accuracy.

Despite this evidence, the Trump administration halted the inclusion of a MENA category in the 2020 Census, citing administrative and procedural concerns. While these concerns echoed earlier bureaucratic justifications—such as definitional ambiguity or the need for more reliable data—they marked a shift in emphasis. Whereas previous delays centered on technical and logistical issues, the 2020 deferral occurred despite robust testing and public feedback in favor of inclusion. In this case, appeals to procedure obscured the political nature of the decision. At a 2018 public meeting, Karen Battle, chief of the Census Bureau's population division, remarked: "We do feel that more research and testing is needed." This bureaucratic hesitation echoes a longstanding pattern: when political will is lacking, appeals to procedural neutrality and technocratic delay become tools of deferral. In the language of Sarah Ahmed, such are nonperformative—not because they fail to act, but because they are uttered in ways that are never meant to bring about the action they name. Ahmed shows that institutions invoke the language of commitment precisely as a way of maintaining the status quo. Here, the invocation

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¹¹⁵ U.S. Census Bureau, *2015 National Content Test (NCT) Race and Ethnicity Analysis Report*, U.S. Census Bureau, 2017, https://www2.census.gov/programs-surveys/decennial/2020/program-management/final-analysis-reports/2015nct-race-ethnicity-analysis.pdf.

¹¹⁶ Ibid., as noted in the report, "When no MENA category was available, people who identified as MENA predominantly reported in the White category, but when a MENA category was included, people who identified as MENA predominantly reported in the MENA category."

¹¹⁷ Hansi Lo Wang, "No Middle Eastern or North African Category on 2020 Census, Bureau Says," NPR, January 29, 2018, https://www.npr.org/2018/01/29/581541111/no-middle-eastern-or-north-african-category-on-2020-census-bureau-says.

¹¹⁸ See Sara Ahmed, "The Nonperformativity of Antiracism," *Meridians* 7, no. 1 (2006): 104–126. Ahmed writes, "In my model of the 'nonperformative', the failure of the speech act to do what it says is not a failure of intent or even circumstance, but it is actually what the speech act is doing," 105.

of "more research" functions less as a step toward inclusion than as a deferral of recognition, allowing the state to appear reflexive and open while reproducing the very invisibility it aims to address. The result is not inaction but performative delay, which extends the cycle of nonrecognition into another census decade.

In March 2024, the OMB officially updated its race and ethnicity standards to include a dedicated MENA category, a long-overdue step toward recognizing these communities in federal data collection. For the first time, MENA individuals will no longer be forced to identify as "White" or select "Other." The Census Bureau has announced that the revised standards will be implemented in the 2027 American Community Survey and the 2030 Census, signaling a significant shift in how racial and ethnic data is collected in the United States. This change reflects decades of advocacy by MENA communities, researchers, and policymakers who have argued that the absence of a distinct category has led to systemic underrepresentation across healthcare, education, and political representation.

Yet, the timing of this shift raises critical questions. The case for a MENA category was already clear by 2015—empirically, methodologically, and morally. Why was recognition withheld until now? What political, demographic, or institutional pressures finally made inclusion advantageous—or at least no longer inconvenient—for the state? If MENA populations

¹¹⁹ "OMB's revisions to SPD 15 add only one new minimum category, Middle Eastern or North African, the addition of which is supported by many years of research, testing, and stakeholder engagement," *Federal Register*, March 29, 2024, https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and.

U.S. Census Bureau, "What Updates to OMB's Race/Ethnicity Standards Mean for the Census Bureau," April 2024, https://www.census.gov/newsroom/blogs/random-samplings/2024/04/updates-race-ethnicity-standards.html.
 OMB 2016 Report on "Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity," September 2016, https://www.federalregister.gov/documents/2016/09/30/2016-23672/standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity This report documents the ongoing debate and push for a separate MENA category, particularly during the Obama administration, and highlights the shift in priorities under the Trump administration, which led to the delay in implementing such a category.

can now be rendered legible within federal data infrastructures, what does that say about the decades they were refused this recognition?

Rather than contradicting the theme of bureaucratic invisibility, the eventual inclusion of a MENA category in 2024 reinforces it. Recognition, in this case, is not evidence of progress; rather, it is a demonstration of how visibility itself is regulated through institutional timing. Bureaucracy does not just preserve invisibility—it paces it, granting recognition when politically expedient. The delayed inclusion of MENA populations reveals visibility as conditional, shaped not by need but by power. Invisibility is not incidental; it is actively sustained through delay, hesitation, and the rhetoric of "not yet."

This thesis does not claim that adding a MENA checkbox will, in itself, resolve the broader harms at stake. Rather, it examines the deeper logic at work: the ways in which racial classification—as a bureaucratic practice—produces structural invisibility while appearing neutral or even benevolent.

What this chapter has traced is not merely the evolution of MENA classification, but the architectural logic of a system that governs by way of categorization. 122 From the historical contingency of MENA's racial legibility to its strategic absorption into the statistical order of whiteness; from procedural delay to the recursive reproduction of invisibility—we have seen that classification does not simply describe, but differentiates, disciplines, and distributes. To be misclassified is not simply to be called by the wrong name, but to be positioned outside the

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¹²² See footnote 68.

frame of recognition itself—to be denied the very terms through which care becomes legible. 123

The final section of this chapter turns explicitly to this ethical dimension. It considers how the bureaucratic logic that has structured MENA invisibility constitutes a form of ethical harm—one that bioethics must account for not as a theoretical concern, but as a material condition shaping the lives and deaths of the [in]visible.

D. Classification as Ethical Harm

This final section turns from the political function of classification to its ethical stakes. What this chapter has traced is not misidentification alone, but a system in which visibility is rationed, and legibility is conditional. What emerges is not just a technical problem, but of moral disregard structured into the architecture of recognition itself. What this chapter has ultimately argued is that politics does not precede ethics—it shapes it. Ethical concern, after all, depends on legibility: it begins where recognition is granted. But when recognition itself is produced through systems of classification, the ethical is already shaped—mediated—by the political. In this light, the harm is not merely a failure of structure, but the decision to structure at all.

To fully grasp this harm, we must turn briefly to the work of Jacques Derrida.

Classification, by its very nature, seeks to stabilize meaning—to name, to sort, to fix what is otherwise unstable. Yet ethics, as Derrida insists, is grounded not in certainty, but in

¹²³ Judith Butler writes, "Such frames structure modes of recognition, especially during times of war, but their limits and their contingency become subject to exposure and critical intervention as well." See *Frames of War: When Is Life Grievable?* (London: Verso, 2009), 24.

¹²⁴ Jacques Derrida, *Of Grammatology*, trans. Gayatri Chakravorty Spivak (Baltimore: Johns Hopkins University Press, 1976), 110. Derrida writes: "Anterior to the possibility of violence in the current and derivative sense, the sense used in 'A Writing Lesson,' there is, as the space of its possibility, the violence of the arche-writing, the violence of difference, of classification, and of the system of appellations."

undecidability.¹²⁵ It is not a matter of applying rules to recognized subjects, but of responding to the singular demand of the other—an encounter that resists codification.¹²⁶ This is why, as Derrida shows, systems built to organize moral concern inevitably exclude that which does not appear in recognizable form. In this light, classification enacts a form of ethical closure: it converts the moral into the administrative, the singular into the sortable.¹²⁷ It forecloses the openendedness on which ethical responsibility depends.

This is the ethical harm at the heart of MENA classification, not just exclusion from visibility, but the prefiguration of visibility itself. To be seen only through the lens of threat—or not at all—is to be denied the ethical singularity that calls for care. The categories that define who count are not merely statistical—they are moral claims. And these claims are shaped by histories of racialization, surveillance, and bureaucratic delay.

Throughout this chapter, we have seen how these systems function: racial categories deployed as political instruments; whiteness preserved as a statistical norm; surveillance regimes that hyper-recognize threat while ignoring need; bureaucracies that defer recognition through the language of neutrality and delay. Derrida helps us see that these are not merely technical decisions. They are decisions that displace the ethical under the guise of order. In reducing

¹²⁵ Jacques Derrida, *The Gift of Death*, trans. David Wills (Chicago: University of Chicago Press, 1995), 5. Derrida writes: "To responsibility in the experience of absolute decisions made outside of knowledge or given norms, made therefore through the very ordeal of the undecidable."

¹²⁶ Jacques Derrida, *Adieu to Emmanuel Levinas*, trans. Pascale-Anne Brault and Michael Naas (Stanford: Stanford University Press, 1999), 10. Derrida writes: "If the relation to the other presupposes an infinite separation, an infinite interruption where the face appears, what happens... when another interruption comes at death to hollow out even more infinitely this first separation?" This underscores how ethical relation depends on an openness that classification forecloses.

¹²⁷ Jacques Derrida reminds us that ethical judgment cannot wait for full knowledge or rest on stable foundations. "A just decision is always required immediately, 'right away.' It cannot furnish itself with infinite information and the unlimited knowledge of conditions, rules or hypothetical imperatives that could justify it." See Jacques Derrida, "Force of Law: The 'Mystical Foundation of Authority'," in *Deconstruction and the Possibility of Justice*, ed. Drucilla Cornell, Michel Rosenfeld, and David Gray Carlson (New York: Routledge, 1992), 26.

¹²⁸ Edward Said, *Orientalism* (New York: Pantheon Books, 1978). Said describes how the Orient is constructed as a threat within dominant Western discourse, making visibility itself a function of suspicion rather than understanding.

recognition to classification, the system offers the appearance of care while denying its possibility. The refusal to interrupt—to let something unanticipated appear—is precisely how ethical harm takes root.

Thus, the moral disregard documented throughout this chapter is not the result of neglect, but the product of a system that was never designed to see. In absorbing MENA populations into whiteness, in framing them as threats, and in rendering their health needs statistically illegible, the classificatory regime ensures that no ethical demand can even appear.

This is why the theoretical labor of deconstruction matters. It is not a retreat from the real, but an exposure of the architecture through which the real is made. 129 It allows us to ask: what are the conditions under which suffering becomes intelligible? 130 And what does it mean when those conditions are designed to exclude?

The answer, and the urgency, lies in the next chapter. There, we follow the material consequences of this foreclosure: in data that omits, in care that arrives too late, in needs that remain untranslatable to the systems tasked with responding. What classification denies, the body reveals. And what remains invisible to the system remains no less real to those who live it.

¹²⁹ See Gayatri Chakravorty Spivak, "Can the Subaltern Speak?" in *Colonial Discourse and Post-Colonial Theory: A Reader*, ed. Patrick Williams and Laura Chrisman (New York: Columbia University Press, 1988), 66–111. Spivak does not aim to recover the subaltern's voice but rather interrogates the institutional and discursive structures that produce and silence it.

¹³⁰ Jeremy Bentham argued that the capacity to suffer—not the ability to reason or speak—should be the basis for moral consideration. His utilitarian framework locates ethical concern in sentience, emphasizing that suffering is a morally relevant experience regardless of one's intellectual or communicative capacities. See *An Introduction to the Principles of Morals and Legislation* (Oxford: Clarendon Press, 1789).

III. Chapter 2: Lived Consequences—Health Disparities in MENA Communities

A. From Structure to Outcome

The limits of classification are nowhere more visible than in the body itself. But what the body discloses is not just what was overlooked—it is what the system was never built to perceive. This chapter begins, then, not with a new object of inquiry, but with a shift in orientation: from the architecture of recognition to its effects. If the previous chapter traced the structural formation of MENA invisibility, this one follows that formation to its consequence—into medicine, into public health, into the intimate scenes of diagnosis, care, and neglect.

To speak of "structure to outcome" is to refuse the abstraction of structure. It is to show that what appears bureaucratic or statistical is also corporeal. The political instruments that define racial categories, the statistical preservation of whiteness, the recursive rationality of bureaucratic delay—these are not merely symbolic acts. They are practices with material consequences.

MENA populations are subsumed under "non-Hispanic White" in federal health data, which prevents their unique health needs from being identified—masking disparities that remain statistically invisible. As Awad et al explain:

Race and ethnicity disparity statistics often exclude the Arab/MENA population because either data are not being collected on this population, or the group is not being disaggregated from the White race category. A growing body of research

shows that Arab/MENA Americans have both health and social patterns distinct from those of Whites.¹³¹

By treating "White" as the analytical default or control, any differences within MENA communities are rendered invisible. Diseases affecting Arab and MENA individuals appear diluted, positioned within the "health norm" of the White reference group, and receive neither the attention nor targeted interventions they require.

Additionally, a comprehensive review by Abuelezam, El-Sayed, and Galea underscores the persistent absence of population-level health data on Arab Americans. Because there is no federal racial or ethnic identifier for this group, researchers are forced to rely on samples drawn from ethnic enclaves—geographic concentrations where Arab American populations are more easily identified. This methodological limitation introduces significant selection bias and prevents the generalization of findings across broader MENA populations. The report notes that "the majority of research is being undertaken among individuals living in ethnic enclaves due to the lack of an ethnic or racial identifier that may help identify Arab Americans from population-based studies," highlighting the structural barriers to producing representative data. Without formal recognition, even health disparities that do exist cannot be reliably measured, let alone addressed.

The limited health data that does exist on Arab Americans is largely the result of researcher ingenuity rather than systemic inclusion. As Lababidi et al. (2024) observe, the issue

¹³¹ Germine H. Awad et al., "Lack of Arab or Middle Eastern and North African Health Data Undermines Assessment of Health Disparities," *American Journal of Public Health* 112, no. 2 (February 2022): 209–12, https://doi.org/10.2105/AJPH.2021.306590;

¹³² N. N. Abuelezam, A. M. El-Sayed, and S. Galea, "The Health of Arab Americans in the United States: An Updated Comprehensive Literature Review," *Frontiers in Public Health* 6 (2018), https://doi.org/10.3389/fpubh.2018.00262.

is not an absence of interest or effort within the medical research community, but rather the structural constraints placed on data collection. Because Arab or MENA identity is not formally recognized in federal health datasets, researchers are compelled to rely on alternative methods—such as community-based sampling, self-identification surveys, or surname algorithms 134—to approximate MENA populations. While these workarounds have generated valuable insights, they lack the scale, consistency, and institutional authority of federal data systems. Consequently, MENA health disparities remain marginalized in public health discourse, reinforcing their political and clinical invisibility.

The progression and transmission of diseases are not solely dictated by biological factors; rather, they emerge from a complex interplay between genomics and a range of sociocultural and environmental stressors. While genetic predispositions may influence susceptibility to certain conditions, the role of chronic stress, structural inequities, and cultural barriers cannot be overlooked.

Chronic stressors—stemming from systemic discrimination, xenophobia, and acculturative stress—can have profound physiological consequences, including dysregulation of immune responses and increased susceptibility to inflammatory diseases. ¹³⁶ As we've seen in the

¹³³ Lababidi, H., Lababidi, G., Rifai, M. A., Nasir, K., and Al-Kindi, S. "Cardiovascular Disease in Arab Americans: A Literature Review of Prevalence, Risk Factors, and Directions for Future Research." *American Journal of Preventive Cardiology*, vol. 18, 2024, p. 100665, https://doi.org/10.1016/j.ajpc.2024.100665.

¹³⁴ Ibid., as Lababidi notes, "Also, in many cases, ArA status was determined using last name, or a combination of first and last name, which may result in some inaccuracies. Many studies have also relied on convenience sampling from local communities rather than true random sampling, due to difficulty in identifying eligible study participants otherwise."

¹³⁵ See Nancy Krieger, *Epidemiology and the People's Health: Theory and Context* (New York: Oxford University Press, 2011), especially Chapter 7, where she outlines an ecosocial theory of disease distribution. Krieger argues that health outcomes must be understood as biologically embodied expressions of social inequality, shaped by intersecting social, environmental, and political conditions over time.

¹³⁶ See footnote 132. "More research on Arab American health is needed to identify risks and needs of this marginalized population given the current social and political climate in the United States, especially with regard to acculturation status and immigrant generation status."

previous chapter, the MENA community experiences hypervisibility in the social and political landscape, particularly through national surveillance programs and the construction of threat narratives. The post-9/11 era saw an escalation of anti-Muslim and anti-Arab hate, policies that framed MENA individuals as security risks, and the widespread surveillance of their communities. A recent study by Patel et al. (2021) found that social risk factors are particularly high among certain MENA ethnic groups, especially non-U.S.-born individuals with low socioeconomic status. Those who experience discrimination or fear deportation face heightened risks, with transportation barriers and food insecurity being the most common challenges. The study also found that individuals with more social risk factors reported worse health outcomes, highlighting the need for targeted screening and referral models to better address the needs of MENA populations in the U.S. 137 The resulting psychological and physiological burden contributes to health disparities, reinforcing the very inequities that remain unaddressed.

Additionally, sociocultural factors such as limited healthcare access, language barriers, and medical mistrust further contribute to disparities in disease outcomes. Many MENA immigrants rely on untrained interpreters, leading to miscommunication and confidentiality breaches. The lack of professional interpretation services worsens treatment adherence, preventive care, and chronic disease management. Several studies confirm that patients with limited English proficiency (LEP) experience higher rates of medical errors, including

¹³⁷ Patel MR et al., "A Snapshot of Social Risk Factors and Associations with Health Outcomes in a Community Sample of Middle Eastern and North African (MENA) People in the U.S.," *Journal of Immigrant and Minority Health* 24, no. 2 (April 2022): 376–384, https://doi.org/10.1007/s10903-021-01176-w.

¹³⁸ Pandey, M., Maina, R. G., Amoyaw, J., Li, Y., Kamrul, R., Michaels, C. R., & Maroof, R., "Impacts of English language proficiency on healthcare access, use, and outcomes among immigrants: a qualitative study," *BMC Health Services Research* 21, no. 741 (2021), https://doi.org/10.1186/s12913-021-06750-4.

¹³⁹ Kwan M, Jeemi Z, Norman R, and Dantas JAR, "Professional Interpreter Services and the Impact on Hospital Care Outcomes: An Integrative Review of Literature," *International Journal of Environmental Research and Public Health* 20, no. 6 (March 15, 2023): 5165, https://doi.org/10.3390/ijerph20065165.

medication mistakes and delayed diagnoses.¹⁴⁰ Immigration status and socioeconomic status compound these issues, further restricting access to quality care and amplifying health vulnerabilities. Immigration status and socioeconomic status compound these issues, further restricting access to quality care and amplifying health vulnerabilities.

When coupled with potential genomic predispositions, these factors create a compounding effect, intensifying health risks and shaping patterns of disease progression within the MENA community. Even when genomic predispositions are considered, they are often viewed through a lens that reinforces race-based medicine rather than addressing how genetic factors interact with structural inequities. Without targeted research, policy changes, and healthcare reforms, MENA populations remain trapped in a system that both over-polices and neglects them, ensuring that their health disparities persist without meaningful intervention.

In addition to disparities in healthcare services, the exclusion of MENA individuals from genomic and clinical research presents another challenge. Arabs remain among the most underrepresented groups in genome-wide association studies (GWAS), accounting for only 0.17% of participants, which significantly hinders the applicability of polygenic risk scores (PRS) and other precision medicine advancements for these populations. Furthermore, the limited inclusion of Arab genomes in research databases—aside from isolated efforts like the Qatar Biobank—fails to capture the genetic diversity of the broader MENA region, exacerbating

¹⁴⁰ Twersky, S. E., Jefferson, R., Garcia-Ortiz, L., Williams, E., & Pina, C. (2024). The impact of limited English proficiency on healthcare access and outcomes in the U.S.: A scoping review. *Healthcare (Basel)*, 12(3), 364. https://doi.org/10.3390/healthcare12030364.

¹⁴¹ See Darshali A. Vyas, Leo G. Eisenstein, and David S. Jones, "Hidden in Plain Sight — Reconsidering the Use of Race Correction in Clinical Algorithms," The New England Journal of Medicine 383, no. 9 (2020): 874-882, https://www.nejm.org/doi/full/10.1056/NEJMms2004740. As Vyas et al. notes, "However, when clinicians insert race into their tools, they risk interpreting racial disparities as immutable facts rather than as injustices that require intervention."

healthcare inequities by perpetuating gaps in knowledge and reinforcing Eurocentric biases in medical research.¹⁴²

The combination of census classification, data dilution, exclusion from minority health initiatives, and documented underrepresentation in genomic and medical research obscures Arab health disparities and perpetuates systemic neglect. Underrepresentation is relative to the actual population size, ¹⁴³ which remains difficult to determine due to the census classification of Arabs as white, further contributing to data dilution. The National Network for Arab American Communities (NNAAC) and other advocacy groups argue that the U.S. Census significantly underestimates the Arab American population due to its classification system. ¹⁴⁴ According to their analysis, alternative estimates place the Arab American ¹⁴⁵ population as high as 3.7 million—more than double the Census Bureau's official count of 1.5 million. ¹⁴⁶ This discrepancy highlights how racial classification shapes political and social recognition rather than reflecting an inherent demographic reality.

Together, these factors—misclassification, data absence, and research exclusion—do more than obscure MENA health disparities; they make those disparities difficult to name,

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¹⁴² Romit Bhattacharya, NingNing Chen, Injeong Shim, et al., "Massive Underrepresentation of Arabs in Genomic Studies of Common Disease," *Genome Medicine* 15, no. 99 (2023), https://doi.org/10.1186/s13073-023-01254-8.

¹⁴³ The phrase "actual population size" does not imply an objective count, as racial and ethnic categories are socially constructed. Instead, it refers to how populations are defined and recognized by institutions—definitions that shape access to resources and representation. The NNAAC's higher estimate relies on methods like surname analysis and community sampling to capture those misclassified under current census categories.

¹⁴⁴ The Arab American Institute Foundation estimates the Arab American population using alternative methods such as ancestry data from the American Community Survey (ACS) and localized community surveys. See *Demographics Report* Census Counts, 2018, https://censuscounts.org/wp-content/uploads/2019/03/National_Demographics_SubAncestries-2018.pdf.

¹⁴⁵ While not all MENA individuals are Arab, Arab Americans represent the largest and most politically organized subgroup within the broader MENA umbrella in the U.S. This estimate is used here to illustrate how undercounting within one major subgroup exemplifies broader challenges in the federal recognition and classification of MENA populations.

¹⁴⁶ Khaled A. Beydoun, *Boxed In: Reclassification of Arab Americans on the U.S. Census as Progress or Peril*, 47 Loy. U. Chi. L. J. 693 (2020). Available at: https://lawecommons.luc.edu/luclj/vol47/iss3/3

measure, or act upon. The consequences are circular: the lack of recognition in federal systems leads to invisibility in public health data, which in turn justifies further exclusion from clinical research, policy priorities, and funding structures. What classification refuses to acknowledge, the clinic cannot reliably treat. The next section turns to these lives: those unaccounted for, uncounted, and undocumented—not just in the legal sense, but in the clinical, ethical, and narrative registers that define access to care.

B. Documenting the Undocumented

a. Cardiovascular Disease

One of the most well-documented health disparities among MENA populations—both in the U.S. and in the MENA region¹⁴⁷—is the high prevalence of cardiovascular disease (CVD). Studies on MENA Americans suggest that, compared to the general U.S. population, they experience higher rates of hypertension, diabetes, and metabolic syndrome, all of which contribute to increased cardiovascular risk.

A recent analysis by Lababidi el al. (2024) found that Arab Americans face a greater odds of developing major cardiovascular conditions than non-Hispanic Whites: coronary artery disease (OR = 1.64, 95% CI 1.54–1.74), myocardial infarction (OR = 1.58, 95% CI 1.45–1.72), heart failure (OR = 1.57, 95% CI 1.45–1.69), and stroke (OR = 1.62, 95% CI 1.46–1.80). An

¹⁴⁷ The National Institutes of Health (NIH) defines the Middle East and North Africa (MENA) region to include Algeria, Bahrain, Cyprus, Djibouti, Egypt, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, Turkey, the United Arab Emirates, and Yemen. However, definitions of MENA can vary among NIH institutes. For instance, the Fogarty International Center includes the Palestinian Territories (Gaza and the West Bank) but excludes Cyprus, Somalia, and Turkey. National Institute of Allergy and Infectious Diseases (NIAID), *NIAID International Research Activities FY 2020: Middle East and North Africa (MENA) Region* (2023), available at niaid.nih.gov.

Lababidi, H., Lababidi, G., Rifai, M. A., Nasir, K., and Al-Kindi, S. "Cardiovascular Disease in Arab Americans: A Literature Review of Prevalence, Risk Factors, and Directions for Future Research." *American Journal of Preventive Cardiology*, vol. 18, 2024, p. 100665, https://doi.org/10.1016/j.ajpc.2024.100665.

odds ratio (OR) greater than 1 indicates increased likelihood; for example, an OR of 1.64 for contrary artery disease means Arab Americans are 64% more likely to develop the condition compared to non-Hispanic Whites. According to El-Sayed et al. (2011), mortality from cardiac disease and cerebrovascular disease is higher among Arab Americans than non-Hispanic Whites, reinforcing concerns about their cardiovascular health. Despite these statistics, significant gaps remain in understanding the root causes and mitigating factors contributing to this heightened risk.¹⁴⁹

Hypertension, diabetes, and metabolic syndrome have all been identified as prevalent conditions contributing to increased cardiovascular risk among Arab Americans. The interplay of genetic predisposition, lifestyle factors, and healthcare access disparities has led to a disproportionately high burden of cardiovascular disease (CVD) in this population. A study by Dallo and Borrell (2006) found a direct association between the duration of residence in the United States and increased blood pressure among Arab Americans, highlighting that the prevalence of hypertension rises with longer stays in the country. Some studies estimate that up to 36.5% of Arab Americans are diagnosed with hypertension, with an additional 39.7% classified as pre-hypertensive. Similarly Lababidi et al. (2024) found that these rates may be linked to multiple factors, including high-sodium diets, obesity, chronic stress due to

¹⁴⁹ A. M. El-Sayed, M. Tracy, P. Scarborough, and S. Galea, "Ethnic Inequalities in Mortality: The Case of Arab-Americans," *PLoS One* 6, no. 12 (2011): e29185, https://pmc.ncbi.nlm.nih.gov/articles/PMC3247248/. Among men, the average annual mortality rate for cardiac disease was 465 per 100,000 for Arab Americans, compared to 422 for non-Arab and non-Hispanic Whites; for cerebrovascular disease, it was 77 vs. 58, respectively. Among women, Arab Americans had a cardiac mortality rate of 284 per 100,000 versus 219 among White women, and 63 vs. 53 for cerebrovascular disease.

¹⁵⁰ Florence J. Dallo and Luisa N. Borrell, "Self-Reported Diabetes and Hypertension Among Arab Americans in the United States," *Ethnicity & Disease* 16, no. 3 (2006): 699–705, https://www.jstor.org/stable/48666895.

¹⁵¹ A. Tailakh et al., "Prevalence, Awareness, Treatment, and Control of Hypertension Among Arab Americans," *Journal of Cardiovascular Nursing* 28, no. 4 (July-August 2013): 330–337, https://doi.org/10.1097/JCN.0b013e31825638ae.

acculturation, and underdiagnosis resulting from healthcare access barriers. The heterogeneity within the Arab American community, including differences in country of origin, socioeconomic status, and length of stay in the U.S., further influences these prevalence rates.

Diabetes, another major CVD risk factor, has been reported in alarmingly high numbers. Lababidi et al. (2024), in their literature review, stated that "the prevalence of type 2 diabetes, a major CVD risk factor, was also markedly higher, ranging 16 % to 41 % in Arab Americans based on objective measures," Similarly, Jaber et al. (2003) found that "among those [MENA] with diabetes, 47.8% of the women and 57.2% of the men were undiagnosed," highlighting the urgent need for improved screening and healthcare access within the Arab American community. This disproportionately high prevalence is likely influenced by both genetic and environmental factors, including higher rates of insulin resistance, sedentary lifestyles, dietary changes post-immigration, and limited access to culturally competent diabetes care.

Additionally, Berlie et al. (2008) suggests that Arab Americans often exhibit poor glycemic control, with a higher proportion displaying HbA1c levels above 9.5% compared to the national population (26.4% vs. 18.0%), leading to higher risks of diabetes-related complications, such as retinopathy, nephropathy, and neuropathy. This trend is consistent with previous findings in other ethnic minority populations.

Hypercholesterolemia is another key contributor to cardiovascular risk in this demographic. Dyslipidemia, particularly low HDL ("good" cholesterol) and elevated LDL

¹⁵² See footnote 148.

¹⁵³ Linda A. Jaber et al., "Epidemiology of Diabetes Among Arab Americans," *Diabetes Care* 26, no. 2 (February 2003): 308–313, https://doi.org/10.2337/diacare.26.2.308.

¹⁵⁴ H.D. Berlie, W.H. Herman, M.B. Brown, A. Hammad, and L.A. Jaber, "Quality of Diabetes Care in Arab Americans," *Diabetes Research and Clinical Practice* 79, no. 2 (February 2008): 249–55, https://doi.org/10.1016/j.diabres.2007.09.003.

("bad" cholesterol) levels, is common in Arab American populations, often exacerbated by dietary factors, smoking, and limited engagement in preventive healthcare. In a study of Arab Americans in Southeast Michigan by Hatahet et al. (2009), the mean total cholesterol concentration was 210 mg/dL in individuals over 40, with HDL levels as low as 38 mg/dL for men and 48 mg/dL for women. Additionally, over 54.6% of participants had a high total cholesterol-to-HDL ratio (>4.5), further increasing their cardiovascular risk. These findings reveal the urgent need for targeted interventions to improve lipid profiles and reduce CVD burden in this population.

Lifestyle factors also contribute significantly to this elevated CVD risk. Waterpipe (hookah) smoking, which is more prevalent in Arab American men compared to the general U.S. population, has been linked to increased risks of hypertension, endothelial dysfunction, and coronary artery disease. Additionally, low levels of physical activity—often due to cultural factors, limited access to safe recreational spaces, and long work hours—exacerbate cardiovascular risk. 156

Beyond biological and lifestyle factors, psychosocial stressors play a critical role in Arab Americans' cardiovascular health. Lababidi et al. (2024) notes that "psychosocial factors may further increase CVD risk, including acculturative stress, discrimination, low health literacy, and barriers to healthcare access." Arab Americans are also less likely to receive preventive

¹⁵⁵ W. Hatahet, P. Khosla, and T.V. Fungwe, "Prevalence of Risk Factors to Coronary Heart Disease in an Arab-American Population in Southeast Michigan," *International Journal of Food Sciences and Nutrition* 53, no. 4 (2002): 325–35, https://pubmed.ncbi.nlm.nih.gov/12090028/.

¹⁵⁶ Stefano Cacciatore et al., "Urban Health Inequities and Healthy Longevity: Traditional and Emerging Risk Factors across the Cities and Policy Implications," *Aging Clinical and Experimental Research* 37, no. 1 (May 7, 2025): 143, https://doi.org/10.1007/s40520-025-03052-1.

healthcare screenings and cardiovascular risk assessments due to lack of insurance, language barriers, and distrust in the medical system.¹⁵⁷

b. Cancer Disparities and Lack of Preventative Care

Arab American women show notably higher rates of thyroid cancer compared to non-Hispanic, non-Arab Whites (NHNAWs) women; a trend observed in studies from California and Detroit. Research suggests that this disparity may be linked to increased exposure to medical and dental radiation, iodine imbalances, or a genetic predisposition common among Middle Eastern populations. Similarly, colorectal cancer incidence among Arab American women in New Jersey is high compared to NHNAW women, which may be attributed to limited access to preventive screenings. Many Arab immigrants face significant barriers to early detection, including financial constraints, lack of awareness about screening guidelines, and language barriers that hinder patient-provider communication.

Bergmans et al. (2014) found that bladder cancer rates among Arab American men are higher than those of NHNAW men, particularly in New Jersey and California, regions with large Egyptian immigrant populations. In Egypt, bladder cancer is prevalent and often linked to schistosomiasis, a parasitic infection that remains rare in the United States. Early-life exposure in

¹⁵⁷ Ali A. Al-Jumaili, Kawther K. Ahmed, and Dave Koch, "Barriers to Healthcare Access for Arabic-Speaking Population in an English-Speaking Country," *Pharmacy Practice (Granada)* 18, no. 2 (April–June 2020): 1809, https://pmc.ncbi.nlm.nih.gov/articles/PMC7243745/#:~:text=Both%20the%20survey%20and%20the,literacy%2C%20particularly%20new%20arriving%20individuals..

¹⁵⁸ K. Nasseri, P. K. Mills, and M. Allan, "Cancer Incidence in the Middle Eastern Population of California, 1988–

¹⁵⁸ K. Nasseri, P. K. Mills, and M. Allan, "Cancer Incidence in the Middle Eastern Population of California, 1988–2004," *Asian Pacific Journal of Cancer Prevention* 8, no. 3 (July–September 2007): 405–411, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2222861/.

¹⁵⁹ R. Bergmans et al., "Cancer Incidence Among Arab Americans in California, Detroit, and New Jersey SEER Registries," *American Journal of Public Health* 104, no. 6 (June 2014): e83–e91, https://doi.org/10.2105/AJPH.2014.301954. Although the difference in thyroid cancer rates between Arab American and non-Hispanic non-Arab White (NHNAW) women was not statistically significant due to small sample sizes, Arab American women in California still had nearly double the age-adjusted incidence. In New Jersey, colorectal cancer rates among Arab American women were also noticeably higher than their NHNAW counterparts.

first-generation immigrants may contribute to the elevated incidence observed in Arab American men. Conversely, prostate cancer rates among Arab American men are significantly lower than those of NHNAW men. This discrepancy may be linked to lower prostate cancer screening rates among Arab immigrants, reflecting patterns observed in other non-White and immigrant populations in the U.S. Limited English proficiency, transportation challenges, and a lack of awareness about screening guidelines have been identified as key barriers to early detection among Arab Americans. These factors likely contribute to reduced screening rates and delayed diagnoses. Additionally, in Arab League nations, prostate cancer incidence is already lower than in Western countries, which may be attributed to differences in screening practices and diagnostic patterns rather than actual disease prevalence. 160

Additionally, regional differences within the U.S. highlight disparities in behavioral risk factors. Arab Americans in California tend to have lower cancer incidence rates than those in New Jersey and Detroit, potentially reflecting regional variations in smoking prevalence.

Smoking rates in New Jersey and Michigan are higher, which may contribute to increased cancer risk in those states. ¹⁶¹

c. Mental Health and Psychological Distress

Studies indicate that Arab Americans experience disproportionately high levels of anxiety, depression, and PTSD compared to the general U.S. population. 162 A study found that

¹⁶⁰ H. Al-Omran, "Measurement of the Knowledge, Attitudes, and Beliefs of Arab-American Adults Toward Cancer Screening and Early Detection: Development of a Survey Instrument," *Ethnicity & Disease* 15, no. 1 Suppl 1 (Winter 2005): S1-15–S1-16. https://pubmed.ncbi.nlm.nih.gov/15787034/

¹⁶² S.Pampati, Z. Alattar, E. Cordoba, M. Tariq, and Ca. Mendes de Leon, "Mental Health Outcomes Among Arab Refugees, Immigrants, and U.S. Born Arab Americans in Southeast Michigan: A Cross-Sectional Study," *BMC Psychiatry* 18 (2018): 379, https://doi.org/10.1186/s12888-018-1948-8.

Arab Americans exhibited significantly higher levels of anxiety and depression compared to standardized and minority community samples, with one-fourth experiencing moderate to severe anxiety and half meeting clinical criteria for depression. Among refugee populations, rates of PTSD are significantly elevated; one study found that 50% of Iraqi refugees resettled in the U.S. met diagnostic criteria for PTSD, with 31% suffering from major depressive disorder.

Several factors contribute to these elevated rates. MENA Americans have experienced heightened discrimination, particularly in the post-9/11 era, which has been linked to increased psychological distress. Arab and Muslim Americans have been disproportionately targeted by surveillance programs, racial profiling, and hate crimes, leading to chronic stress and anxiety. Additionally, acculturative stress—navigating identity conflicts between American and MENA cultural values—has been shown to contribute to feelings of isolation and distress, particularly among younger generations. 167

d. Insurance and Socioeconomic Status

Middle Eastern and North African (MENA) immigrants in the United States face significant disparities in healthcare access due to systemic barriers related to language, insurance

¹⁶³ Amer, Mona M., and J. D. Hovey. "Anxiety and Depression in a Post-September 11 Sample of Arabs in the USA." *Social Psychiatry and Psychiatric Epidemiology* 47, no. 3 (2012): 409–18. https://doi.org/10.1007/s00127-011-0341-4.

¹⁶⁴ Eboni M. Taylor, Emad A. Yanni, Clelia Pezzi, Michael Guterbock, Erin Rothney, Elizabeth Harton, Jessica Montour, Collin Elias, and Heather Burke, "Physical and Mental Health Status of Iraqi Refugees Resettled in the United States," *Journal of Immigrant and Minority Health* 16 (2014): 1130–1137, https://doi.org/10.1007/s10903-013-9893-6.

¹⁶⁵ Kader, F., Bazzi, L., Khoja, L. *et al.* "Perceived Discrimination and Mental Well-being in Arab Americans from Southeast Michigan: a Cross-Sectional Study," *J. Racial and Ethnic Health Disparities* 7, 436–445 (2020). https://doi.org/10.1007/s40615-019-00672-y.

¹⁶⁶ Awad GH, Kia-Keating M, Amer MM. "A model of cumulative racial-ethnic trauma among Americans of Middle Eastern and North African (MENA) descent," Am Psychol. 2019 Jan;74(1):76-87. doi: 10.1037/amp0000344. https://pubmed.ncbi.nlm.nih.gov/30652901/.

¹⁶⁷ A. R. Suleiman, O. Afify, and K. E. Whitfield, "The Effect of Stress, Acculturation, and Heritage Identity on Depression in Arab Americans," *Journal of Community Hospital Internal Medicine Perspectives* 11, no. 4 (2021): 433–38, accessed March 1, 2025, https://doi.org/10.1080/20009666.2021.1929050.

coverage, socioeconomic status, and immigration status. Research has shown that MENA immigrants who do not identify as White are more likely to experience delayed care, provider discrimination, and unmet medical needs, highlighting the impact of racial and citizenship-based disparities. While the Affordable Care Act (ACA) initially helped reduce racial disparities in healthcare access, structural inequalities persist, particularly for MENA communities that are often overlooked in public health research. Additionally, anti-immigrant sentiment and Islamophobia further marginalize these populations, discouraging them from seeking necessary care. To

One of the most pressing challenges is access to employer-sponsored insurance. Many MENA immigrants work in small businesses or are self-employed, making them less likely to receive health coverage through an employer.¹⁷¹ Even among those with higher incomes, uninsurance remains prevalent. For example, research shows that while Arab Americans in California tend to have higher wealth than those in Michigan, they still report higher rates of uninsurance, indicating that income alone does not guarantee healthcare access.¹⁷² Immigration-related challenges, including restrictive eligibility for public insurance programs, further exacerbate these disparities. Non-citizens are significantly less likely to have a regular healthcare provider, visit a doctor annually, or seek preventive care, even when they have chronic

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¹⁶⁸ Samari, G., Sharif, M. Z., & Alcalá, H. E., "Racial and Citizenship Disparities in Health Care Among Middle Eastern Americans," *Medical Care*, 58(11), 974–980, https://doi.org/10.1097/MLR.0000000000001423.

¹⁶⁹ Buchmueller, T. C., Levinson, Z. M., Levy, H. G., & Wolfe, B. L., "Effect of the Affordable Care Act on Racial and Ethnic Disparities in Health Insurance Coverage," *American Journal of Public Health*, 106, 1416–1421, https://doi.org/10.2105/AJPH.2016.303155.

¹⁷⁰ Samari, G. (2016). "Islamophobia and Public Health in the United States," *American Journal of Public Health, 106*, 1920–1925. https://doi.org/10.2105/AJPH.2016.303374.

¹⁷¹ New American Economy. (2019). *Middle Eastern and North African immigrants in the United States*. https://www.newamericaneconomy.org/wp-content/uploads/2018/07/MENA-Report.pdf

¹⁷² Abuelezam, N. N., El-Sayed, A. M., & Galea, S., "Differences in health behaviors and health outcomes among non-Hispanic Whites and Arab Americans in a population-based survey in California," *BMC Public Health* 19, 892 (2019), https://doi.org/10.1186/s12889-019-7233-z.

conditions that require ongoing management. This hesitancy to seek care is often linked to fears of discrimination, legal repercussions, and financial burdens associated with out-of-pocket medical expenses.¹⁷³

Language barriers further complicate access to healthcare for MENA immigrants.

Limited English proficiency delays care, weakens patient-provider relationships, and leads to misunderstandings about diagnoses, treatments, and medications. Many immigrants rely on untrained interpreters, such as family members or community members, which often results in misinterpretation and breaches of confidentiality. The lack of professional interpretation services contributes to lower treatment adherence, reduced use of preventive screenings, and poorer chronic disease management, ultimately worsening health outcomes. Without proper language support, many MENA individuals feel disconnected from the healthcare system, leading to dissatisfaction and reluctance to seek medical help unless absolutely necessary.

C. Reframing Disparities Through Bioethics

To conclude this chapter is not to resolve the disparities it has traced, but to reframe what those disparities mean. If the previous sections have followed how misclassification structures medical harm—from clinical trials to mistrust—then this final section turns toward the

¹⁷³ Dondero, M., & Altman, C. E., "Immigrant policies as health policies: State immigrant policy climates and health provider visits among U.S. immigrants," *SSM - Population Health* 10 (2020): 100559, https://doi.org/10.1016/j.ssmph.2020.100559.

¹⁷⁴ Pandey, M., Maina, R. G., Amoyaw, J., Li, Y., Kamrul, R., Michaels, C. R., & Maroof, R., "Impacts of English language proficiency on healthcare access, use, and outcomes among immigrants: a qualitative study," *BMC Health Services Research* 21, no. 741 (2021), https://doi.org/10.1186/s12913-021-06750-4. "In the absence of universal interpretation services across the country, healthcare providers rely on professional interpreters, interpreters from community-based organizations and/or ad hoc (untrained) interpreters such as family members, friends, and volunteers who lack understanding of medical terminology and disease,"

¹⁷⁵ Kwan, M., Jeemi, Z., Norman, R., & Dantas, J. A. R., "Professional Interpreter Services and the Impact on Hospital Care Outcomes: An Integrative Review of Literature," *International Journal of Environmental Research and Public Health* 20, no. 6 (2023): 5165, https://doi.org/10.3390/ijerph20065165.

¹⁷⁶ See footnote 173. "Language barriers also impeded effective communication between healthcare providers and clients, leading to suboptimal care and dissatisfaction with the care received,"

conceptual work required to respond. Disparities are not just statistical imbalances. They are ethical injuries that emerge from the conditions of visibility itself. They reflect not only what the system fails to record, but whom it was never structured to see. Reframing these disparities through the lens of bioethics requires a shift: from understanding misrecognition as a technical error to seeing it as a moral failure embedded in the very design of public health.

As argued in Chapter 1, classification enacts an ethical closure. It sorts and stabilizes meaning in ways that foreclose the undecidability upon which ethical responsibility depends.¹⁷⁷ When medicine relies on these categories to identify need, it replicates the same exclusions. Health disparities, then, are not the unfortunate byproduct of a lagging system; they are the predictable expression of a system that only knows how to recognize what it has already anticipated.

This is where bioethics must intervene. Not as an afterthought to medical practice, but as a critical site for rethinking what recognition demands. A bioethics that responds to MENA classification must begin with the premise that harm is not only clinical but epistemic. 178 It must refuse the temptation to treat disparities as gaps in knowledge alone and instead understand them as symptoms of a deeper violence: the violence of being rendered unintelligible to the systems tasked with care. 179

Such a reframing allows us to see strategic reforms not as final answers, but as temporary interruptions—ways to expose the political function of categories and the ethical costs of

¹⁷⁷ See footnote 125.

¹⁷⁸ See Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (New York: Oxford University Press, 2007). Fricker introduces the concept of epistemic injustice to describe how marginalized groups are wronged specifically in their capacity as knowers, a foundational harm in systems of healthcare misrecognition. ¹⁷⁹ See footnote 129.

remaining within them. Strategic interventions—such as data disaggregation, provisional MENA categorization, or community-based research—do not resolve the ethical foreclosure described in Chapter 1. But they do interrupt it. They make the harm visible. They break the illusion that justice can be built upon a classificatory system that institutionalized disregard in the first place.

This is the work of bioethics: not only to ask what care is owed, but to interrogate how that question is structured, and by whom. ¹⁸⁰ In doing so, it returns ethics as a disruptive force—as the site where the refusal to fit becomes the very ground for moral responsibility. If Chapter 1 uncovered the architecture of misrecognition, and this chapter has followed how that architecture materializes in medicine, then this final section suggests that bioethical response must remain vigilant: mindful that reforms operate within a system shaped by exclusion, and aware that justice cannot be presumed from recognition alone.

This sets the stage for Chapter 3. There, I will explore what kinds of reforms are possible—not as solutions, but as interventions that, by nature, are partial, situated, and strategic.¹⁸¹ I ask how public health and bioethics might act not by resolving classification, but by troubling it: exposing its assumptions, resisting its closures, and insisting that care remain open to those it has historically misrecognized.¹⁸²

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¹⁸⁰ Turner, L. Bioethics in a Multicultural World: Medicine and Morality in Pluralistic Settings. *Health Care Analysis* 11, 99–117 (2003). https://doi.org/10.1023/A:1025620211852, Turner writes, "thus far, leading principlists have also failed to respond to anthropological critiques of the methods, theories, and disciplinary assumptions of bioethics," urging greater attention to how bioethics itself participates in the exclusions it often overlooks.

¹⁸¹ Donna Haraway, Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective, Feminist Studies 14, no. 3 (1988): 579. This draws from Haraway calling to hold together "radical historical contingency," an awareness of "our own 'semiotic technologies' for making meanings," and a "nononsense commitment to faithful accounts of a 'real' world."

¹⁸² Didier Fassin, *Life: A Critical User's Manual* (Cambridge: Polity Press, 2018). Fassin dedicates a chapter to the "politics of life," analyzing how institutions govern life unequally—granting visibility, care, or protection only to those deemed legible or valuable within dominant moral frameworks.

IV. Chapter 3: Bioethics and the Politics of Recognition

A. Strategic Reforms, Not Resolutions

This section does not propose a way out. Rather, it asks what might be done within—without presuming that the system which classifies can be perfected by inclusion alone.

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Interventions are forms of strategic friction.
184 Their value lies not in resolving classification, but in disclosing its terms: making visible what has been historically denied recognition and distributing resources along lines long ignored. These reforms do not repair the structure—they interrupt it, however briefly. They reveal that to act ethically within a flawed system is not to endorse its categories, but to work critically through them. This may involve subverting categories, but it might also include amplifying community-led data practices, reimagining care outside bureaucratic legibility, or developing new infrastructures of recognition that are not beholden to state taxonomies. Ethical action, then, is not singular—it is plural, contextual, and often contradictory.

a. <u>Provisional Category</u>

A provisional MENA category would function as a time-bound, context-specific classification introduced explicitly to address existing gaps in data, funding, and public health intervention. It would be implemented not as a permanent fixture of federal racial taxonomy, but as a targeted corrective. In practice, this would involve incorporating a dedicated MENA checkbox in key federal instruments such as the American Community Survey (ACS), National

¹⁸³ See footnote 2. Sarah Ahmed critiques how inclusion efforts often reproduce the very structure they claim to challenge, revealing the limits of reform from within.

¹⁸⁴ See Chandra Talpade Mohanty, *Feminism Without Borders: Decolonizing Theory, Practicing Solidarity*, (Durham: Duke University Press, 2003), 37. Mohanty argues that "strategic coalitions that construct oppositional political identities for themselves are based on generalization and provisional unities, but the analysis of these group identities cannot be based on universalistic, ahistorical categories."

Health Interview Survey (NHIS), and datasets maintained by the CDC and NIH. ¹⁸⁵ The category would be accompanied by clear methodological documentation; its purpose would be explicitly stated as corrective and provisional, with periodic evaluations to assess both its impact and its limitations. Agencies could adopt a flexible coding scheme that distinguishes MENA respondents from both "White" and other recognized minority groups, allowing for disaggregated analysis without presuming fixed identity boundaries.

Crucially, the design and deployment of this category would require deep engagement with community organizations, scholars, and public health practitioners to define its parameters—ensuring it reflects the diversity of MENA populations across nationality, religion, and migration history without flattening them into a monolithic bloc. The provisional nature of the category means it would be reviewed every 5–10 years, with sunset clauses or modification protocols written into policy. ¹⁸⁶ This not only encourages reflexivity but protects against bureaucratic ossification. In this form, the MENA category becomes a tactical infrastructure that does not pretend to resolve classification's harms but leverages the state's own tools to name, count, and address what its systems have long refused to see.

To further ensure that the category operates as an intervention rather than a resolution, several complementary measures could be introduced. First, a dual-track categorization system would allow individuals to be identified as MENA alongside the existing racial categories,

¹⁸⁵ According to the U.S. Census Bureau, National Content Test (NCT) findings show that "the use of a distinct MENA category elicits higher quality data; and people who identify as MENA use the MENA category when it is available, whereas they have trouble identifying as only MENA when no category is available," (*Research to Improve Data on Race and Ethnicity*, U.S. Census Bureau, December 20, 2024, https://www.census.gov/about/our-research/race-ethnicity.html).

¹⁸⁶ Deborah Stone notes that some policies are crafted with "built-in provisions for an amendment process," providing "a mechanism for [their] own adaptation" (*Policy Paradox: The Art of Political Decision Making*, W.W. Norton & Company, 2012, 298). This supports the use of sunset clauses and review protocols as safeguards against bureaucratic inertia and as tools for reflexive governance.

enabling researchers to map historical misclassification and track disparities over time without disrupting longitudinal datasets.¹⁸⁷ This would provide a transitional framework to assess the impact of reclassification.

Second, any implementation must be accompanied by federal investment in analytic infrastructure—including funding opportunities specifically tied to MENA health research, workforce development in data analysis, and public-facing reports that translate findings into actionable insights. Without such support, the provisional category risks becoming symbolic rather than transformative.

Third, the establishment of ethical oversight mechanisms—such as community-informed advisory boards or public accountability reports—would guard against the category's misuse, especially given the long history of surveillance targeting Arab and Muslim communities. 188

Lastly, data governance must center consent and community control. Participatory models, where communities help determine how their data are interpreted and used, can ensure that inclusion does not become another form of dispossession. The goal is not just to be seen, but to shape the terms of visibility. ¹⁸⁹ In this way, the provisional category becomes a site of ethical intervention. This will produce data not as truth, but as demand. It is political in its orientation, temporary in its design, and accountable in its consequences.

¹⁸⁷ The revised OMB Standards (SPD 15, 2024) and related Census research endorse a combined race/ethnicity question that allows respondents to select multiple categories—e.g., both MENA and White—without disrupting historical data trends. https://www.census.gov/newsroom/blogs/random-samplings/2024/04/updates-race-ethnicity-standards.html.

¹⁸⁸ J. Herington, K. Connelly, and J. Illes, "Ethical Imperatives for Working With Diverse Populations in Digital Research," *Journal of Medical Internet Research* 25 (2023): e47884, https://doi.org/10.2196/47884.

¹⁸⁹ Jemal Demeke, Fiqir Worku, and Tiyondah Fante-Coleman, *Existing Models of Community Governance of Health Data* (Toronto: Wellesley Institute, 2024), https://www.wellesleyinstitute.com/wp-content/uploads/2024/10/Existing-Models-of-Community-Governance-of-Health-Data.pdf.

b. Community-led Initiatives

Where state visibility ends, community begins. In the long shadow of classification's erasure, Arab and MENA communities have created their own infrastructures of care—not as proxies for state intervention, but as counter-logics to its omissions. These are not merely stopgap solutions to systemic neglect; they are enactments of care rooted in relational accountability, cultural specificity, and lived epistemologies. They ask not only who is counted, but who is known—and how.

Organizations like El Mahaba in Nashville emerge precisely from this tension. Formed to serve Arab immigrants, including many with undocumented status or limited English proficiency, El Mahaba provides translation, college preparation, health advocacy, and mutual aid. It does so not through the language of metrics, but through trust: built over time, across generations, and in defiance of institutions that have long classified these communities out of existence. Though not medical in focus, its work directly addresses the social determinants of health—education, language, legal precarity—that shape whether care can be accessed at all.¹⁹⁰

In places like Dearborn, Michigan, ACCESS (Arab Community Center for Economic and Social Services) has developed one of the most robust community health frameworks in the country—offering mental health counseling, tobacco cessation programs, refugee health assessments, and domestic violence support. These are services not simply translated into

¹⁹⁰ El Mahaba Center. *About Us.* Nashville, TN. https://www.elmahabacenter.com/home-1-1.

Arabic, but culturally transformed: responsive to histories of migration, intergenerational trauma, and the specific burden of being surveilled as a racialized threat in American life.¹⁹¹

Such organizations are not passive recipients of policy failure. They are producers of knowledge in their own right. They track disparities that national datasets ignore. In doing so, they reveal the epistemic violence of data invisibility: that harm does not require recognition to exist, only to be addressed.

Yet community-led work, for all its ingenuity, remains structurally constrained. Most operate without stable funding streams. Their labor is often unpaid, emotional, and feminized. 192 Many are overlooked by academic and policy institutions that valorize "evidence-based" interventions while ignoring the forms of evidence communities have long produced. 193 These initiatives are frequently asked to partner, to consult, to lend credibility, while remaining peripheral to the systems that claim to serve them. 194

What would it mean, then, to not just fund or partner with community-based organizations, but to recenter them as epistemic authorities? To treat their insights not as anecdotal supplements to federal data, but as demands that reorient what public health even

¹⁹¹ ACCESS (Arab Community Center for Economic and Social Services). Dearborn, MI. https://www.accesscommunity.org/.

¹⁹² Felicity Butler, "Valuing Unpaid Labour in Community Fair Trade Products: A Nicaraguan Case Study from The Body Shop International," *Gender and Development* 22, no. 3 (November 2014): 533–547, https://www.jstor.org/stable/24697508.

¹⁹³ Kayla Tawa, *Redefining Evidence-Based Practices: Expanding Our View of Evidence* (Washington, DC: CLASP, May 15, 2020), https://www.clasp.org/publications/report/brief/redefining-evidence-based-practices-expanding-our-view-evidence/.

¹⁹⁴ Umair Majid, "The Dimensions of Tokenism in Patient and Family Engagement: A Concept Analysis of the Literature," *Journal of Patient Experience* 7, no. 6 (December 2020): 1610–1620, https://doi.org/10.1177/2374373520925268.

means? This shift would involve an ethic of co-production, where communities ¹⁹⁵—not institutions—set research agendas, define what success looks like, and retain control over how their data are interpreted and disseminated. ¹⁹⁶ It would require long-term, unconditional funding infrastructures that prioritize the health of the community over the priorities of grant cycles. It would mean expanding the scope of what counts as data to include oral histories, testimonies, and cultural archives—not as narrative adornments, but as central to any serious engagement with health disparities. ¹⁹⁷ And it would require feedback loops in which these communities are not merely consulted, but empowered to reshape the very public systems that claim to serve them. ¹⁹⁸

In the context of a provisional MENA category, community-led initiatives become indispensable as reminders of what that logic has never been able to see. They do not seek inclusion for its own sake but insist that recognition must be reciprocal: if the state seeks to name MENA communities, those communities must have the power to define what that name means, when it applies, and when it does not. To support these efforts is not to fix classification, but to interrupt its authority, and to create space for forms of knowledge and care that classification

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¹⁹⁵ By "ethic of co-production," I refer to frameworks that prioritize community governance in research and policy design. While models vary, examples include participatory action research (PAR), community advisory boards (CABs), and deliberative democratic processes such as consensus conferences or ranked-choice deliberations. These methods differ in how they select representatives, structure decision-making, and define authority. The practical challenges—of who speaks, who decides, and how legitimacy is conferred—remain unresolved, but they do not negate the ethical imperative to redistribute epistemic power. See Sheila Jasanoff, *Designs on Nature: Science and Democracy in Europe and the United States* (Princeton, NJ: Princeton University Press, 2005) and Amy Gutmann and Dennis Thompson, *Why Deliberative Democracy?* (Princeton, NJ: Princeton University Press, 2004), for discussions of co-production and democratic legitimacy in public knowledge systems.

¹⁹⁶ S. R. Carroll et al., "The CARE Principles for Indigenous Data Governance," *Data Science Journal* 19, no. 1 (2020): 43, https://datascience.codata.org/articles/10.5334/dsj-2020-043.

¹⁹⁷ Sarah G. Hernandez et al., "Oral Histories as Critical Qualitative Inquiry in Community Health Assessment," *Health Education & Behavior* 44, no. 5 (October 2017): 705–715, https://doi.org/10.1177/1090198117728546.

¹⁹⁸ Emma K. Tsui and Amy Starecheski, "Uses of Oral History and Digital Storytelling in Public Health Research and Practice," *Public Health* 154 (January 2018): 24–30, https://doi.org/10.1016/j.puhe.2017.10.008.

cannot contain. In this sense, community-led initiatives do not resolve the problem of misrecognition; they outlive it.

c. Embedding Recognition in Care

Lastly, in the clinical setting itself, this would mean embedding questions of identity, language access, ¹⁹⁹ and migratory history²⁰⁰ directly into intake processes, as optional fields, but as standard, ethically necessary components of care. While some institutions already ask about language preference or offer interpretation services, these practices are often inconsistent, siloed, or treated as peripheral to clinical judgment.²⁰¹ A more rigorous approach would integrate these elements into the heart of diagnosis and care planning, recognizing that structural legibility shapes not only communication, but trust, treatment outcomes, and even clinical imagination.

But visibility does not end with data fields. It is inscribed in the physical and symbolic space of the hospital itself. Who is represented on posters and pamphlets? What languages are visible on signage? Which cultures are centered in staff training or food menus?²⁰²

To counter this, visibility must become not just an act of data collection but an ethic of design. Intake forms could allow for fluid self-identification that reflects intersecting identities. Electronic health records could permit updates to demographic markers as identity evolves.

¹⁹⁹ Rose L. Molina and Jennifer Kasper, "The Power of Language-Concordant Care: A Call to Action for Medical Schools," *BMC Medical Education* 19, no. 1 (November 6, 2019): 378, https://doi.org/10.1186/s12909-019-1807-4. ²⁰⁰ Kayvan Bozorgmehr et al., "Integration of Migrant and Refugee Data in Health Information Systems in Europe: Advancing Evidence, Policy and Practice," *The Lancet Regional Health – Europe* 34 (October 27, 2023): 100744, https://doi.org/10.1016/j.lanepe.2023.100744.

²⁰¹ According to a CMS issue brief summarizing a Medscape provider survey, "one third of respondents asked patients about language needs at intake and 10% track patient language preferences in medical records" (*How Healthcare Providers Meet Patient Language Needs: Highlights of a Medscape Provider Survey*, Centers for Medicare & Medicaid Services, September 2017), https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Issue-Brief-How-Healthcare-Providers-Meet-Patient-Language-Needs.pdf.

²⁰² M. J. Hashim, M. S. Alkaabi, and S. Bharwani, "Interpretation of Way-Finding Healthcare Symbols by a Multicultural Population: Navigation Signage Design for Global Health," *Applied Ergonomics* 45, no. 3 (May 2014): 503–509, https://doi.org/10.1016/j.apergo.2013.07.002.

Clinics could adopt narrative-based tools that invite patients to contextualize their health within their lived experiences.²⁰³ In this way, the clinical encounter becomes a site not only of treatment but of recognition: a place where the histories that shape illness are not background noise but essential data.

This is not a call for cosmetic inclusion, but for a deeper infrastructural shift—one that reimagines visibility as both a clinical tool and a form of justice.

B. Epistemic Injustice and the Ethics of Knowing

To conclude this chapter, and this thesis, is not to close the inquiry but to name the ethical terrain it has crossed. The harms traced throughout—from the bureaucratic architectures of classification to their clinical consequences—are not only structural or material; they are epistemic. That is, they concern who is permitted to know, to be known, and to produce knowledge that matters.

Epistemic injustice, as articulated by philosopher Miranda Fricker and others, refers to the ways in which individuals or communities are wronged specifically in their capacity as knowers. For MENA populations in the United States, this injustice is inscribed in the very systems meant to generate knowledge. When MENA individuals are subsumed under "White," their health data disappear. When researchers cannot locate them in datasets, the burden shifts to communities to prove their own suffering. And when those communities generate knowledge—

²⁰³ Neil K. Aggarwal et al., "Patient Identity Narratives Through the Cultural Formulation Interview in a New York City Outpatient Clinic," *Medical Anthropology Quarterly* 37, no. 3 (September 2023): 280–295, https://doi.org/10.1111/maq.12781.

²⁰⁴ See footnote 178.

through oral history, mutual aid, or community health initiatives—that knowledge is often dismissed as anecdotal, unscientific, or outside the scope of institutional legitimacy.

To speak of the ethics of knowing, then, is to ask not only what public health or bioethics can see, but how they see, and through what structures of authority. The demand is not merely for inclusion in existing epistemologies, but for a transformation of the epistemic frame itself.²⁰⁵ It is a call to reimagine what counts as evidence and which ways of knowing deserve institutional regard.

The reforms outlined in this chapter are not solutions to epistemic injustice. They do not fix the system that misrecognizes; they disclose its terms and attempt, briefly, to redistribute the power those terms conceal. In this way, the work of bioethics is not to resolve what classification has broken. It is to remain ethically accountable to what cannot be resolved. A bioethics that takes misclassification seriously must resist the closure of recognition as its only aim. ²⁰⁶ It must remain open to what eludes category, to what defies neat assimilation, to what insists that care be responsive even to those who remain officially unrecognized.

Strategic interventions are not endpoints but ethical gestures; they are ways of holding open the space between harm and recognition, data and justice. To know ethically is not to

²⁰⁵ Ian James Kidd and Havi Carel, "Healthcare Practice, Epistemic Injustice, and Naturalism," in *Harms and Wrongs in Epistemic Practice*, ed. Simon Barker, Charlie Crerar, and Tristan S. Goetze (Cambridge: Cambridge University Press, 2018). PMID: 32997467.

²⁰⁶ Havi Carel and Ian James Kidd, "Epistemic Injustice in Healthcare: A Philosophical Analysis," *Medicine, Health Care and Philosophy* 17, no. 4 (2014): 529–40, https://doi.org/10.1007/s11019-014-9560-2.

finalize identity, or to perfect systems of care. It is to stay with what those systems cannot see, and to insist that even what is uncounted still counts.²⁰⁷

²⁰⁷ Emmanuel Levinas, *Totality and Infinity: An Essay on Exteriority*, trans. Alphonso Lingis (Dordrecht: Kluwer Academic Publishers, 1991), 198: "The face speaks to me and thereby invites me to a relation incommensurate with a power exercised, be it enjoyment or knowledge."

V. Conclusion: The Ethics of What Remains

To conclude this thesis is not to locate its endpoint but to articulate the aperture it opens. The question of MENA classification, though seemingly narrow in scope, reveals a broader, more enduring problem at the heart of modern ethical inquiry: how systems designed to care for life are themselves conditioned by the structures that delimit which lives appear, and in what form. This is not a problem that bioethics can simply resolve. It is a problem that calls bioethics into question.

This project has not argued for the wholesale reform of bioethics. It has not suggested that the field is broken, nor that its tools are without value. Rather, it has insisted on a slower, more difficult proposition: that bioethics, in its current form, is shaped by the very classifications it seeks to interrogate. It does not stand outside of racial systems as their critic. It is folded within them, absorbing their categories, epistemologies, and exclusions as the condition of its own authority. The case of MENA populations does not sit at the periphery of this problem; it reveals its structure.

Classification, as this thesis has argued, is not simply a means of organizing populations for the sake of clarity or efficiency. It is a political instrument. It produces legibility and illegibility in unequal measure. When MENA populations are absorbed into "whiteness," their particular vulnerabilities—rooted in histories of displacement, surveillance, and racialization—are rendered statistically invisible. This is not an error in need of correction. It is the outcome of a system that equates neutrality with normativity, and normativity with whiteness.

Bioethics, as a field, depends on classification to frame its questions: who is a patient, what constitutes harm, what forms of life are worth preserving. Yet it rarely examines the

classificatory assumptions embedded in its frameworks. The invisibility of MENA populations is not simply a gap in data; it is epistemic violence—one that emerges not from the absence of knowledge, but from its overdetermination. The category "white," presumed to be neutral, absorbs difference into a universal that cannot hold it. Bioethics, when it takes this neutrality for granted, becomes complicit in the very forms of exclusion it might otherwise critique.

What this thesis has sought to demonstrate, then, is not the failure of bioethics to see, but the conditions under which it sees at all. The tools it uses—recognition, visibility, justice—do not emerge in a vacuum. They are shaped by political histories, bureaucratic practices, and institutional inheritances that precede the ethical moment. To reframe MENA misclassification as a bioethical concern is not to make a political issue ethical. It is to reveal how ethics is already entangled in the political.

This entanglement does not render bioethics irrelevant. It renders it accountable. It demands a form of inquiry that does not stop at naming injustice but questions how injustice is made knowable in the first place. Provisional categories, community-based research, and restructured clinical practices are methodological disruptions. They remind us that reform, when untethered from critical analysis, can become another form of concealment. What matters is not simply what changes, but how change is understood—what it discloses, what it preserves, what it forecloses.

Of course, objections remain. Some may argue that the current data are insufficient for concrete policy shifts, or that introducing a MENA category could divert already limited resources. Others may worry that "MENA" itself is too heterogeneous to operate as a stable or meaningful classification. These concerns are not dismissed here. They are acknowledged as part

of the terrain that any ethical intervention must navigate. But lack of a perfect category cannot justify continued inaction. The absence of targeted recognition has measurable consequences: unmet health needs, uncounted disparities, and communities rendered invisible in systems designed to distribute care. To act provisionally is not to act without care—it is to act in response to existing harm, using imperfect tools with conscious intention.

While this thesis has focused on the case of MENA classification, further comparative analyses—particularly alongside groups such as Hispanic or Asian Americans who have received official recognition—may help substantiate the broader stakes of this inquiry.

Examining how federal classification has facilitated data collection, policy development, or health interventions for these groups could sharpen our understanding of what targeted recognition makes possible, and where it falls short. Such comparisons lie beyond the scope of this project, but they offer a promising direction for future research—one that could further illuminate both the potential and the limits of recognition as an ethical and political tool.

If bioethics is to meet this challenge, it must learn to inhabit its discomfort. It must ask how its own foundations have been structured through the exclusions it now seeks to address. It must remain attuned to what exceeds its language, what resists its frameworks, and what insists on another kind of visibility—one not captured by the checkbox or stabilized by the survey. Ethics, in this account, is not the application of principle. It is the willingness to remain proximate to what cannot yet be resolved.

The work, then, is not to finish, but to return—again and again—to the residues that classification leaves behind, to the edges where language falters, to the lives that resist the terms laid out for their legibility. Reform may mark a shift, but it cannot redeem a system that made

invisibility its foundation. Bioethics, if it is to mean anything here, must learn to dwell in that tension—not to resolve it, but to remain accountable to what exceeds its reach. What remains is not a unified subject waiting to be recognized on its own terms, but a fractured and contested field of experience that resists the very frameworks through which recognition is granted.

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