# Part 2: Why narratives matter

Narratives can be understood as collective stories, or systems of meaning. These stories are woven into the fabric of everyday life; they circulate widely and are embedded in our national psyche. They "provide the necessary mental models, patterns, and beliefs to make sense of the world and our place within it." They shape our language, our thinking, and our actions. They are mostly taken for granted and accepted as natural, when in fact they are not. They are expressed in a wide variety of formats, including legal codes, the arts, mass media, corporate reports and scientific literature.

Narratives are embedded in the structure of the health care system, and in the ways in which we think about patients, families, communities and neighborhoods we serve—and even ourselves. For example, certain narratives guide physicians' and other health care providers' thinking about "non-compliance" (itself an outdated term rooted in a power differential that places blame on patients), just as other narratives guide their thinking about cultural norms in the communities they serve. Narratives shape public opinions regarding health care reform and guide our interpretation of health equity statistics, along with the guestions we ask about the causes of adverse health outcomes.

Consider the narratives that come to mind when you begin to think of the following situations:

- A 44-year-old Puerto Rican man comes to a free clinic with acute exacerbation of back pain. He has diabetes and hypertension. He is hesitant to seek health care. He expresses a mistrust of institutions because of negative experiences with the criminal justice system.<sup>39 ‡</sup>
- A 60-year-old Black woman presents at the emergency department of a community hospital in the south side of Chicago with a breast lump. She does not have a regular doctor.<sup>14</sup>

Narratives shape what questions we ask in these cases and what solutions we might develop. They even shape our descriptions of the situation, what attributes of the person and the situation are emphasized in our summary of the cases. The circumstances of the 44-year-old man suffering from back pain ultimately requires us to grapple with the immediate concern of back pain, the longer term concerns about controlling his diabetes and hypertension, *and* the structural violence associated with hyperincarceration.<sup>39</sup> In the case of the 60-year-old woman, we are tasked with helping her access appropriate testing and treatment while confronting the structural racism that has shaped the economic opportunities as well as limited access to quality treatment in her community.<sup>14</sup> Even the use of "free clinic" puts a pejorative narrative that undermines equity and exposes the reality of a two-tier, segregated health care system. Both cases represent an opportunity to "shift the narrative"—from the traditional biomedical focus on the individual and their behavior to a health equity focus on the well-being of communities, as shaped by social and structural drivers.

<sup>†</sup> Racial and Ethnic Disparities in Health Care H-350.974

<sup>#</sup> Improving Healthcare in Hispanic Populations in the United States 2008 - H-350.975, Racial and Ethnic Disparities in Healthcare 2019 H- 350.974, Improving the Health of Black and Minority Populations 2011- H-350.972, Redefining AMA's Position on ACA and Healthcare Reform 2017 D-165.938.

This guide discusses how dominant narratives obscure historical legacies and harmful power structures that affect people's well-being. Dominant narratives serve to uphold social and economic relations that privilege some and marginalize others. They shape our thinking and assessment of the world around us. They determine who we "see" and whose needs are and aren't prioritized. Importantly, dominant narratives shape our understanding of what we deem possible and not possible.

One important way to make narratives visible is to consider the language we use in our work. Take, for example, the widely used term "vulnerable population," a term often used to describe groups that exhibit increased susceptibility to adverse health outcomes. We even describe individuals as vulnerable or not vulnerable, often based on their socioeconomic status or neighborhoods in which people live. If we pause to examine our unconscious narrative, we can see that vulnerability can be understood in very different ways. In this case, it is used as a characteristic of people or groups—as something they "have."

But what if we shift the narrative from an individualistic lens to an equity lens? That leads to questions directed toward the structural origins of vulnerability.<sup>40,41</sup> Instead of stigmatizing individuals and communities for being vulnerable, we begin to recognize the conditions and power relations that create vulnerability. People are not vulnerable; they are made vulnerable.

Similarly, it is not for the advantaged in society to "empower" communities; an equity lens allows us to recognize that systems of power and oppression (including white supremacy, homophobia, xenophobia, ableism) shape institutional policies and living conditions that systematically harm populations. An equity lens opens up new and profound ways of framing questions, as explored in Table 3.

Table 3: Changing the Questions We Ask

Conventional	Health equity perspective
What interventions can address health disparities?	What generates health inequity in the first place?
What social programs and services are necessary to address health inequity?	What types of social change is necessary to confront health inequity?
How can individuals protect themselves against health problems?	What kind of public collective action is necessary to confront health inequity across identifiable populations?
How can we promote healthy behavior?	How can we democratize land use policies through greater public participation to ensure healthy living conditions?
How do we treat the consequences of health inequity?	How do we act on root causes of inequality to meet human need?
How can we create more resilient communities?	How can public health protect communities from disinvestment, redlining, predatory lending, serving as targets for hazardous waste?
What are the ways public health can adapt innovative practices to changing times?	What are the ways public health, with their allies, can organize for social change directed to meeting human need for health and well-being?

Source: NACCHO, "Advancing Public Narrative for Health Equity & Social Justice" report.

<sup>§</sup> Racial and Ethnic Disparities in Health Care H-350.974

These examples reveal a deeper point: our language reflects underlying systems of power. Ibram X. Kendi, in Stamped from the Beginning: *The Definitive History of Racist Ideas in America*, describes how racist ideas grow *out* of discriminatory policies, not the other way around.<sup>42</sup> Ideas, expressed in words and narratives, are grounded in economic and political power that advantage some and disadvantage others.

Reframing our language in this way (for example, rethinking our use of "vulnerability") opens up possibilities for reimagining health interventions; it shifts the focus from the personal/behavioral to the structural. Jonathan Metzl and Helena Hansen describe this as "structural competence," the trained ability to understand how issues typically defined clinically as symptoms, attitudes or diseases (e.g., depression, hypertension, obesity, smoking, medication "non-compliance," and even trauma) also represent the downstream manifestations of a number of upstream structural drivers: social inequities, institutional policies and living conditions.<sup>22</sup> There are now a growing set of tools for assessing "structural vulnerability" in health care settings and a growing commitment among many health systems to push upstream to address the root causes of health inequities in their communities.<sup>41</sup>

### **Examining dominant narratives**

Dominant narratives reflect the values and interests of the dominant group—white, wealthy, hetero-, able-bodied, male, Christian, U.S.-born. Challenging dominant narratives often involves, indeed requires, re-thinking language and word choice from the perspective of those outside this group. Twenty years ago, for example, health equity was a term rarely used in the United States. Instead, we often used health disparities, a term now widely recognized as limited to a description of difference. Health inequities, in contrast, came to be defined as health differences that are unjust, avoidable, unnecessary, and unfair—no longer a simple calculus of difference, but an assessment based on a value judgment.<sup>2</sup> The change in terminology was important, signaling a shift in our understanding and interpretation of the data. The shift in narrative ushered social justice concerns from the margins to the center.

Generally, narratives are collections of related, shared stories or explanations that circulate in society and produce systems of meaning enabling people to make sense of the world and how it works. They provide shared explanations of who we are as a nation and what functions government should perform. Because these narratives become inscribed in our consciousness from an early age, often as common sense, who is telling the stories is not always clear.

Dominant narratives are deeply rooted, ingrained, widespread stories, explanations or cultural practices that give preference to the interests of society's most powerful social groups, often based on race, class, gender, sexual orientation, physical ability and other characteristics used to oppress other groups. For example, dominant narratives explain economic inequities as the result of market forces, or the large gaps in life expectancy found among different population groups as due to individual behavior. These narratives are powerful because they can influence the legitimacy of public agendas and acceptable policy. Subconsciously reinforcing and repeating stories over time can sustain inequity by obscuring its causes (and responsible parties), making injustice appear natural and inevitable. Consider the examples in Table 4, drawn from the work of the National Association of County and City Health Officials (NACCHO), in its influential report, "Advancing Public Narrative for Health Equity & Social Justice":

Table 4: Features of Dominant Narratives in Everyday Life

Feature	Example
Dominant narratives absolve people and institutions of responsibility for social injustice.	Economic crises are said to be caused by markets, mistakes, unfortunate events, rather than decisions and choices made by institutions and networks of power.
Dominant narratives justify policy decisions by quantifying them with a precise cost. The purpose is to give the appearance of objectivity, even when the value of social goods, such as education, have value and benefit that cannot simply be determined by its cost as an ordinary commodity.	Cost-benefit analysis used to determine market values or prices to things including clean air, water quality and non-renewable natural resources.
Dominant narratives use economic indicators—rather than social indicators of well-being—as main measures of value and importance, including human life.	Dow Jones Industrial Average, productivity, consumer confidence, GDP, earnings ratios.
Dominant narratives use coded racial language to feed on insecurities of the white majority; they stoke resentment and distract from threats that might otherwise unite people across racialized groups, such as concentrated wealth and the destruction of the environment.	Coded racial words and phrases like inner-city, colorblind, states' rights, welfare queen, tough on crime, and government handout are used to denigrate public services that are needed and paid for by all but become associated with minoritized groups.
Dominant narratives underwrite social divisions and drive wedges among racial groups, workers, genders and other groups so that they do not see their common concerns.	Relies on othering, stigmatizing, categorizing, and creating competition, hierarchies and divisions by social status.
Dominant narratives position people as consumers rather than citizens; choices are defined through individual consumption rather than broad social policy, serving as a substitute for democracy.	Freedom is defined as choice to buy, sell, own, have purchasing preferences, yet not as having civil rights, or making democratic decisions based on living conditions or social accountability
Dominant narratives blame people for their own condition by placing the cause of their problems on the individuals themselves, and not on systems that generate inequity.	Causes of illness are due to personal irresponsibility.

Source: NACCHO, "Advancing Public Narrative for Health Equity & Social Justice" report.

Dominant narratives are found everywhere in culture, not only in language. They exist in the public consciousness and cultural memory, reinforced in stories, images, symbols, myths, practices, customs, art, mass media, textbooks, fiction and more. Often resistant to change, they become normalized and unquestioned, like stories about the founding of the United States, a slave-holding society where only propertied white men could vote. Dominant narratives protect and advance the interests of privileged social groups, often dividing populations with common concerns, and obscuring alternative visions of what is possible.

The important purpose that underlies the close examination of dominant narratives is to demystify and correct distortions of reality, thereby revealing the interests and history behind structures of power that perpetuate social injustice. One important aspect of health equity work is to create the conditions for telling the stories of those who have been excluded.

Yet, narratives are not static. They are constantly changing due to contradictions and resistance, and require continuous validation. Earlier in this guide, we introduced two medical cases: a 44-year-old man with acute back pain and a 60-year-old woman presenting at a community hospital with a lump in her breast. 14,39 Both situations could be

interpreted within the dominant narrative, focusing on biomedical issues and individual behaviors. Yet both situations also called for a much deeper and nuanced analysis to fully understand the dynamics of *structural violence* at play.<sup>43</sup> In both cases, one could change the narrative and generate alternative explanations (and possible solutions) for the cases.

Consider, for example, the overwhelming focus on changing individual behavior to improve health, mostly avoiding the social and economic conditions which generate poor health outcomes—this individualistic focus reflects dominant narratives.<sup>3</sup> Or the narratives often present in medical discourse around patient "non-compliance." Non-compliance is often used to blame patients for not following through with their health plan—ignoring the significant barriers faced by patients in their lives, from not having enough money to pay for their medications, or not having the capability to take time off work, or not being able to secure affordable childcare to participate in an activity or follow up appointment. Conventional and equity-focused root-cause narratives are illustrated in Table 5:

Table 5: Contrasting Conventional (Well-intentioned) Phrasing with Equity-focused Language that Acknowledges Root Causes of Inequities

Conventional	Revision
Native Americans have the highest mortality rates in the United States.	Dispossessed by the government of their land and culture, Native Americans have the highest mortality rates in the United States.
Low-income people have the highest level of coronary artery disease in the United States.	People underpaid and forced into poverty as a result of banking policies, real estate developers gentrifying neighborhoods, and corporations weakening the power of labor movements, among others, have the highest level of coronary artery disease in the United States.
Factors such as our race, ethnicity or socioeconomic status should not play a role in our health.	Social injustices including racism or class exploitation, e.g., social exclusion and marginalization, should be confronted directly, so that they do not influence health outcomes.
For too many, prospects for good health are limited by where people live, how much money they make, or discrimination they face.	Decisions by landowners and large corporations, increasingly centralizing political and financial power wielded by a few, limit prospects for good health and well-being for many groups.

Source: NACCHO, "Advancing Public Narrative for Health Equity & Social Justice" report.

Dominant narratives' power to override alternative viewpoints precludes the imagining of a more just society. Omnipresent and insidious, dominant narratives can slip inside our heads and actions without our awareness, as the Grassroots Policy Project observes. Dominant narratives are created and advanced for a purpose and can endure for generations. Yet dominant narratives lose some of their power when they are unmasked for what they are—tools for creating and reinforcing power.

Consider, for example, the workings of the following two dominant narratives (which hold power in society overall and in health in particular), the narrative of race and the narrative of individualism.

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#### The narrative of race

Camara Jones defines race as "a socially constructed way of grouping people, based on skin color and other apparent physical differences, which has no genetic or scientific basis."<sup>45</sup> Yet in many aspects of medicine, race continues to be used as a biological concept.<sup>13</sup> The practice of using race as a biological construct (racial essentialism) results in harm for historically marginalized and minoritized groups, exacerbating health inequities. Race-based protocols currently exist (and are being challenged) in a wide range of areas: eGFR (estimated glomerular filtration rate), BMI risk for diabetes, FRAX (fracture risk assessment score), PFT (pulmonary function test), UTI (urinary tract infection), ASCVD (atherosclerotic cardiovascular disease) and more. As seen in Figure 2, race-based medicine leads directly to racial health inequities (adding to and compounding the health effects of racism that exists outside of the medical sector), with harmful practices in research, medical education and clinical practice.<sup>35</sup>

Research Medical education Clinical practice Race-based medicine Racial groups understood as inherently diseased Race ill-defined and Racial health inequities inferred to have biological significance Biologised concepts of race reinforced Race-conscious medicine Support provided to Consequences of racism on Race defined as a social Reduction in racial health health taught and power construct inequities barriers to health

Figure 2: How Race-based Medicine Leads to Racial Health Inequities Through Research, Medical Education and Clinical Practice

Source: Cerdeña, Plaisime, and Tsai, 2020. The Lancet. 35 Used with permission.

Directly challenging dominant narratives about race, new AMA policies passed in 2020 explicitly (a) denounce racism as a public health threat; (b) call for the elimination of race as a proxy for ancestry, genetics, and biology in medical education, research, and clinical practice; and (c) decry racial essentialism in medicine. Also in 2020, the AAMC released a new framework, Addressing and Eliminating Racism at the AAMC, in Academic Medicine, and Beyond, that outlines concrete steps the AAMC will take to address structural racism across all fronts: as individuals, as an association, as part of the academic medicine community, and as members of society. Senior leaders in medical education have worked with the AAMC to provide guidance to educators on actions towards anti-racism in medical education including acknowledging the misuse of race throughout medical training that creates an improper connection for learners and perpetuates the theory of biologically derived racial differences (racial essentialism).

This is a true turning point. The use of race as a proxy variable across centuries of medical, epidemiological, and genetics research has contributed to histories of painful interventions, delayed medical treatment, erroneous medical decision-making, and has oftentimes locked historically marginalized and minoritized peoples out of life-enhancing or life-saving healthcare delivery.<sup>50</sup> A biological narrative of race is threaded within the fibers of our oldest social institutions, and the policies that govern them.<sup>51</sup>

The implications of this are profound. As explained by Dorothy Roberts:

"There is a long history of using a biological definition of race to make social inequities seem natural—the result of inherent difference instead of societal injustice. ... The claim that race-based biotechnologies will shrink the gap based on genetic difference is a powerful way to deflect concerns about their unjust social impact and the social inequality that actually drives poor health in marginalized/minoritized groups. We should be against an approach that promotes individual health through technological cures as a way of ignoring larger social inequities." 52

Yet narratives that reinforce racial essentialism exist everywhere in society, expressed in beliefs, symbols, stereotypes, values, and institutional practices in banking, education, criminal justice, and in the health care system itself. These narratives constantly shift and adapt as conditions change and serve to rationalize the privileges of racism that sustain white supremacy. They perpetuate cumulative advantage and unearned benefits for whites, often blaming people of color for their own conditions, avoiding social accountability for racist oppression. Thus, racism functions as a "fundamental cause of disease," impacting multiple health outcomes through various pathways: close off one and others are there to maintain the relationship between racism and health.

One does not have to read very far in the medical literature before coming across research on racial differences in health that posit biological or genetic reasons for observed differences. Rhea Boyd et al. have issued a powerful rebuke of this practice: "In the absence of a rigorous examination of racism, assertions that unmeasured genetic or biological factors may account for racial differences in health outcomes are troublingly frequent." They draw out critical implications:

"The academic publication process, through authors, reviewers, and editors, has legitimized scholarship that obfuscates the role of racism in determining health and health care. This renders racism less visible and thus less accessible as a preventable etiology of inequity. It enables the health care infrastructure to unduly blame individual patients for the neglect and harm of systemic processes that undergird individual and population health inequities. It subjects countless patients, spanning generations in communities of color, to ineffective behaviorist approaches to problems that are actually institutional in nature." 56

It is past time to shift the narrative from *race to racism*—recognizing, as critical race scholarship teaches us, that race is a socially-constructed system for producing and reinforcing power. Again, Dorothy Roberts explains and directly challenges physicians:

"... [R]ace is not a biological category that naturally produces these health disparities because of genetic difference. Race is a social category that has staggering biological consequences ... because of the impact of social inequality on people's health. ... What if doctors joined the forefront of a movement to end the structural inequities caused by racism, not by genetic difference?" (emphasis added)<sup>57</sup>

Our work must recognize how systems of power intersect to create and reinforce inequities, particularly based on race. This means that we must invest in data infrastructure to collect race and ethnicity data, while continuing to challenge and disavow essentialist or biological explanations of race-based differences. In other words, we need race and ethnicity data to fully understand, challenge and overcome racial inequities in society.

We lead with race because history and the evidence compel us to do so. Racial inequities, representing some of the largest gaps amongst populations in this country, exist and persist in every system examined across the country: health care, education, criminal justice, employment and housing. Conversations about race and racism also tend to be some of the most difficult for people in this country to participate in for numerous reasons, including a lack of knowledge or shared analysis of its historical and current underpinnings, as well as outright resistance and denial that racism exists. Given the deep divides that exist between groups in the United States, understanding and empathy can be extremely challenging for many because of an inability to really walk a mile in another's shoes" in a racialized sense. This creates fissures that have to be overcome when seeking to achieve a space of understanding. Engaging in anti-racist work requires both a personal commitment to an internal process of working through the trappings of white supremacy and dominant narratives.

We recognize that across other dimensions of marginalization (including gender, gender identity, sexual orientation, disability, age, class/socioeconomic status, citizenship status and language), structural racism remains a significant injustice. It is critical to address all areas of marginalization and inequity due to sexism, class oppression, homophobia, xenophobia and ableism. This recognition calls for us to apply an intersectional approach, a "race AND \_\_\_\_\_\_" approach, in which we continually acknowledge that these overlapping identities create unique modes of advantage and oppression.

#### The narrative of individualism

Individualism is a philosophy and group of ideas, expressed in symbols, practices, and stories that supports a belief that self-sufficient individuals are rational beings that freely make consumer-like choices, independent of political influences, living conditions or historical context. Among these ideas is the concept of meritocracy, a social system in which advancement in society is based on an individual's capabilities and merits rather than on the basis of family, wealth or social background. Individualism is problematic in obscuring the dynamics of group domination, especially socioeconomic privilege and racism.<sup>58</sup> In health care, this narrative appears as an over-emphasis on changing individuals and individual behavior instead of the institutional and structural causes of disease.<sup>58</sup>

This narrative acknowledges that class inequities may be unfortunate, but falls short of declaring them unjust, thus obscuring political, structural and social determinants of health inequities. Diseases become the main target rather than the social and economic conditions that produce health inequities. <sup>59</sup> This focus ignores the role of political struggle in the advances that have been made over time. <sup>60</sup> For example, the major advances in life expectancy in the early 20th century resulted from the actions of social movements to eliminate child labor, institute housing and factory codes, and raise living standards, not advances in technology or economic growth. <sup>60</sup> Health promotion in medicine and public health typically means educating people as individuals about their health without acknowledging the influence of living conditions, which are themselves conditioned upon

societal, structural inequalities.<sup>3,61,62</sup> We argue that much can be gained by shifting this narrative, from the individual to the structural, in order to more fully understand the root causes of health inequities in our society.

## The purpose of a health equity-based narrative

There are many dominant narratives that attribute health to personal choices (weight, drug/alcohol abuse, preventive health care) without taking into consideration equity in the greater society. However, it is almost impossible to be or stay healthy in an *unhealthy environment*. Consider the health effects of living in chronically disinvested neighborhoods, with poor quality and unsafe housing, with limited options for exercise and healthy foods, expensive or unreliable public transportation, a dearth of pharmacies and an overabundance of fast-food outlets. The harmful effects of these characteristics are the basis of the social determinants of health model, as well as newer models that go even further "upstream" to the root causes of health inequities.

We have seen that a dominant narrative in health care regards health as a personal responsibility. The prominent social epidemiologist Nancy Krieger calls this the "medical and lifestyle" explanation of health inequities. It focuses on biological explanations of disease, treatable and amendable through health care and individual-level behavior change. Krieger argues that this narrative is limited and ignores social context, leading to a simplistic understanding of the causes of health inequities. This dominant narrative does not take into consideration social justice, but rather, looks at people and/or communities failing or succeeding with no bearing of responsibility by the systems and structures of power influencing their lives.

A health equity-based public narrative would:

- Focus attention on inequitable systems, hierarchies, social structure, power relations, and institutional practices to reveal the sources of inequalities and the mechanisms that sustain them.
- Avoid both blaming individuals for their condition or assuming that inequity can be resolved through programmatic fixes that ignore the social responsibility of corporations and government agencies.
- Encourage public dialogue on structural racism and all forms of oppression and inequity to encourage a broad public response.
- Foster efforts to strengthen community-driven initiatives that fundamentally improve well-being

A health equity narrative grounded in equity and a social justice framework also would:

- Provide possibilities and the space to reflect, engage and fearlessly advance possibilities for a more just society.
- Highlight examples drawing on experiences from throughout the world.
- Expose the political roots underlying apparently "natural" economic arrangements, such as property rights, market conditions, gentrification, oligopolies and low wage rates.