

Racism and Discrimination in Healthcare: What Role for Bioethics?

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RACISM AND DISCRIMINATION IN HEALTHCARE: WHAT ROLE FOR BIOETHICS?

ABSTRACT: The objective of this paper is twofold. Firstly, the different forms of racism and discrimination in healthcare are explored and framed in a three-level analysis which includes practices, policies, and knowledge. Secondly, the paper translates such analysis into the current bioethics debates to provide an overview of the possible tools and strategies bioethics can put in place to mitigate and contrast racism and discrimination in healthcare. This is meant to stimulate a higher awareness among the bioethics community about the role that we as scholars and our discipline as a field of knowledge can play in fighting racism and discrimination in healthcare, which in turn is fundamental to contribute to more just, inclusive and equitable healthcare systems and societies.

KEYWORDS: Racism and discrimination, social justice, race, genomics, healthcare inequalities

SUMMARY: 1. Introduction – 2. Practices, policies, and knowledge – 2.1. Practices – 2.2. Policies – 2.3. Knowledge – 2.3.1. The discreet charm of race in genetics and genomics – 2.3.3. Race-tailored medicine – 2.3.4. The Standards – 3. What role for bioethics? – 3.1. Practices – 3.2. Policies – 3.3. Knowledge production – 4. Conclusions.

1. Introduction

Racism is commonly defined as “prejudice, discrimination, or antagonism directed against a person or people based on their membership in a particular racial or ethnic group, typically one that is a minority or marginalized”¹. Racism in healthcare is a global phenomenon, dating back to and analyzed by substantial literature². As known, the immediate effect of racism in healthcare is discrimination to the detriment of people belonging to racialized groups. Discrimination in healthcare negatively affects service accessibility but also its efficacy, thus leading to severe inequalities³.

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¹ Oxford Languages, Definition of Racism. Oxford Learner's Dictionaries. <https://www.oxfordlearnersdictionaries.com/us/> (last visited 01/10/2024).

² S. MERZ, T. AKSAKAL, A. HIBTAY, H. YÜCESOY, J. FIESELMANN, K. ANNAÇ, et al., *Racism against healthcare users in inpatient care: a scoping review*, in *International Journal of Equity Health*, 23, 1, 2024, 89; M. PATTILLO, S. STIEGLITZ, K. ANGOUNIS, N. GOTTLIEB, *Racism against racialized migrants in healthcare in Europe: a scoping review*, in *International Journal of Equity Health*, 22, 1, 2023, 201; Z.D. BAILEY, N. KRIEGER, M. AGÉNOR, J. GRAVES, N. LINOS, M. BASSETT, *Structural racism and health inequities in the USA: evidence and interventions*, in *The Lancet*, 389, 10077, 2017, 1453-1463.

³ A. ELIAS, Y. PARADIES, *The Costs of Institutional Racism and its Ethical Implications for Healthcare*, in *Journal of Bioethical Inquiry*, 18, 1, 2021, 45-58; C. FINCHER, J.E. WILLIAMS, V. MACLEAN, J. ALLISON, C. KIEFE, J. CANTO, *Racial disparities in coronary heart disease: a sociological view of the medical literature on physician bias*, in *Ethnicity and Disease*, 14,

The COVID-19 pandemic has provided a clear example of the magnitude of this problem⁴. As it has been argued: “While COVID-19-specific mortality rates in many African nations remained low throughout the pandemic non-Hispanic Black people in the USA were much more likely to die from the disease than their white counterparts, even after adjusting for age, comorbidities, and sociodemographic disparity”⁵.

The relation of bioethics with racism and discrimination is a paradoxical one. Bioethics indeed arose in the past century, mostly as a reaction to the racist crimes perpetrated under the aegis of healthcare, such as the atrocities of Nazi medical experimentations, or the outrageous Tuskegee Syphilis study conducted in Alabama (US) from 1932 to 1972. However, the vocation of bioethics scholars for the *cutting-edge* and the *technology-driven* has slowly faded to the background the relevance of the cultural, social, and economic factors in health and healthcare – and therefore also in bioethics⁶. In other words, despite racism and discrimination in healthcare have been among the main inputs for the foundation of bioethics, in less than a century, their importance has been resized to the advantage of ethical dilemmas and critical issues posed by new advancements in medicine⁷.

While most of the available scholarship focuses on the effects of racism and discrimination, less effort has been put into analyzing their roots, including the structural connections these phenomena hold with bioethics itself as a discipline. In such a context, this paper aims at *taking seriously* the relationship between bioethics and racism and discrimination in healthcare. This unfolds a few questions of departure: is bioethics effective or at least well-equipped in the fight against racism and discrimination? Is bioethics aware of all the facets that racism and discrimination can assume today? Is the training of bioethicists (and health professionals) adequate to combat racism and discrimination? Is the production of knowledge in bioethics free from racist stereotypes, categories, hypotheses, and classifications, or, on the contrary, does that knowledge contribute to the perpetuation of racism and discrimination?

The objective of this paper is twofold. Firstly, the different forms of racism and discrimination in healthcare are explored, paying particular attention to how they unfold across the structure of industrialized societies. To fulfill this objective, racism and discrimination in healthcare are framed in a three-level analysis which includes practices, policies, and knowledge. These elements can be analyzed from top to bottom based on their impact on racism and discrimination in healthcare (see Fig. no. 1). More in detail, a specific dimension of racism and discrimination in healthcare will be coupled with each of the three levels, namely medical racism, institutional racism, and epistemic racism.

3, 360-371; S. Morel, *Inequality and discrimination in access to urgent care in France ethnographies of three healthcare structures and their audiences*, in *Social Science and Medicine*, 232, 2019, 25-32

⁴ M. VASQUEZ REYES, *The Disproportional impact of COVID-19 on African Americans*, in *Health Human Rights*, 22, 2020, 299-307.

⁵ M. ETTI, M. YUAN, J. BUMP, *Sun, skin and the deadly politics of medical racism*, in *BMJ Global Health*, 8, 2023.

⁶ C. BOTRUGNO, *Diritto alla salute e migrazioni internazionali: per una bioetica in azione*, in *Jura Gentium*, 16, 2, 2019, 102-126; G. BERLINGUER, *Everyday Bioethics: Reflections on Bioethical Choices*, New York, 2003; G. BERLINGUER, *Bioetica quotidiana*, Firenze, 2000; L. TURNER, *Bioethics, public health, and firearm-related violence: missing links between bioethics and public health*, in *Journal of Law, Medicine & Ethics*, 25, 1997, 42-48; L. TURNER, *Bioethics needs to rethink its agenda*, in *British Medical Journal*, 328, 7432, 2004, 175.

⁷ C. BOTRUGNO, M. M. RAYMUNDO, L. RE, *Bioethics and racism: Practices, conflicts, negotiations and struggles*, Berlin, 2023.

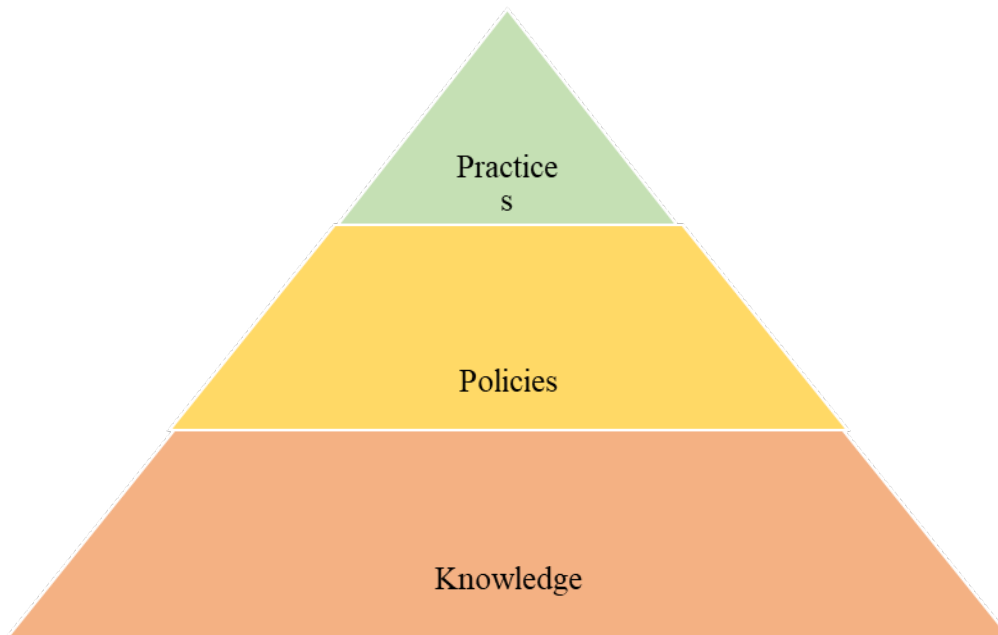


Fig. 1 - The three levels of racism in healthcare

Secondly, this paper seeks to translate this three-level analysis into the current bioethics debates on racism and discrimination to provide an overview of the possible tools and strategies bioethics can put in place to mitigate and contrast racism and discrimination in healthcare. This is meant to stimulate a higher awareness among the bioethics community about the role that we as scholars and our discipline as a field of knowledge can play in fighting racism and discrimination in healthcare, which in turn is fundamental to contribute to more just, inclusive and equitable healthcare systems and societies.

2. Practices, policies, and knowledge

2.1. Practices

The word “practice” derives from the Ancient Greek *praxis* which was used to refer to *action*. Today, practices refer to behaviors (or actions) that are usually carried out in a specific context by a determined group of people, in most of the cases being used in the professional field. From this perspective, practices may be seen therefore as habits, or else the result of the mutual interaction between material and non-material factors that contribute to shaping professional cultures. The latter can be seen as a direct expression of the collective identity of a group of professionals insofar as they exert a significative influence on their attitudes, visions, orientations, and goals.

This is also valid when considering racist-informed practices in healthcare and their impact on health outcomes⁸. To further analyze this first and most evident level of racism in healthcare I will refer to the notion of *medical racism*. Such a notion is still missing a precise definition in the literature given the huge variety

⁸ D. WILLIAMS, J. LAWRENCE, B. DAVIS, *Racism and Health: Evidence and Needed Research*, in *Annual Review of Public Health* 40, 2019, 105-125.

of expressions used to refer to racism and discrimination in healthcare. To provide a more detailed reference, I retake the general definition of racism from the introduction and apply it to healthcare delivery or the point of care. Therefore, medical racism can be intended as any prejudice, discrimination, or antagonism from a healthcare professional or a patient against a person or people based on their membership in a particular social group.

Medical racism can find its roots in one or more overlapping factors. These may include phenotypical traits such as skin pigmentation or other physical connotations which assume the value of *markers* of a specific group (thought to be race or ethnicity), or socio-economic factors like education, employment, gender, and sexual orientation. The legal status is another main factor leading to medical racism, as shown by a huge body of evidence⁹. Not least, the mere circumstance of belonging to a determined cultural or religious group, particularly where notions of culture and religion are essentialized and exasperate, can turn into a proxy for medical racism¹⁰.

By reviewing evidence reporting cases of medical racism¹¹, the following types of racist-informed practices among healthcare professionals can be found: i) professionals who refuse to assist some patients, ii) professionals who dedicate less attention, less time, less concentration, or show less availability towards some patients, iii) professionals who treat worse or disattend standards of care when caring for some patients, iv) professionals who question some patients regarding their lifestyles, habits, choices in the field of health.

Medical racism can lead to clearly visible discriminatory effects, including patients' lack of recognition and consideration, as well as the stigmatization of their cultures, attitudes, beliefs, opinions, and preferences, which contribute to their repression and invisibilization. All this results in severe healthcare inequalities, which have a direct impact on racialized patients, harming them and provoking suffering and death. However, the magnitude of medical racism is bigger than it appears in reality. Indeed, only a small part of episodes of medical racism is brought to the surface, creating a sort of *iceberg effect*. Most of these episodes remain hidden for reasons that are easy to understand and are mostly related to the asymmetric power relations underlying the interaction between healthcare professionals and patients in the

⁹ T. MATOSE, G. MAVIZA, W. NUNU, *Pervasive irregular migration and the vulnerabilities of irregular female migrants at Plumtree border post in Zimbabwe*, in *Journal of Migrant Health*, 5, 100091, 2022; A. LEBANO, et al., *Migrants' and refugees' health status and healthcare in Europe: a scoping literature review*, in *BMC Public Health*, 20, 1, 2020, 1039; S. PRIEBE, D. GIACCO, R. EL-NAGIB, *Public Health Aspects of Mental Health Among Migrants and Refugees: A Review of the Evidence on Mental Health Care for Refugees, Asylum Seekers and Irregular Migrants in the WHO European Region*, Copenhagen, 2016; C. BOTRUGNO, *Everyday Bioethics, Migrations, and Healthcare: Weighing the difference*, in *L'Altro Diritto*, 2018, 1, 78-101.

¹⁰ K.D. PYKE, *What is internalized racial oppression and why don't we study it? Acknowledging racism's hidden injuries*, in *Sociological Perspectives*, 53, 2010, 551-572.

¹¹ S. MOREL, op. cit.; D. WILLIAMS et al., op. cit.; W. SIM et al., *The perspectives of health professionals and patients on racism in healthcare: A qualitative systematic review*, in *Plos One*, 16, 8, 2021; C. FITZGERALD, S. HURST, *Implicit bias in healthcare professionals: a systematic review*, in *BMC Medical Ethics*, 1, 18, 2017, 19. W. HALL, et al., *Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review*, in *American Journal of Public Health* 105, 12, 2015, e60-e76; W. MAINA, T. BELTON, S. GINZBERG, A. SINGH, T. JOHNSON, *A decade of studying implicit racial/ethnic bias in healthcare providers using the implicit association test*, in *Social Science and Medicine*, 2018, 199, 1982, 219-229.

economic-driven and bureaucratic organization of healthcare systems in industrialized countries¹². When moving from the awareness that patients stand in a position of vulnerability in front of the modern healthcare apparatus¹³, it is easy to understand that those patients belonging to racialized groups will face even more difficulties in reporting or bringing to the light episodes in which they have been discriminated. This can simply occur because they might fear the repercussions of their objections – i.e., being refused or receiving inadequate care –, or just because they feel shame due to the racial abuse itself. To a certain extent, the episodes of medical racism may remain hidden because they are not perceived as such, which refers to a mechanism of “embodiment”¹⁴ by racialized people who have naturalized racism, and thus believe that any form of denigrating or discriminatory attitudes directed towards them is *normal*, simply because it is current practice in a determined context¹⁵.

Racist practices, however, do not only affect patients. Evidence also shows race-, ethnic, or country-based discriminatory attitudes from patients toward healthcare professionals¹⁶ as well as a myriad of career disadvantages and other job-related abuses associated with belonging to a racialized group¹⁷. As in the case of racialized patients, healthcare professionals who suffer racism may also be brought to hide racist episodes concerning them, especially if they belong to less qualified personnel categories, or in any case they are in a position in which they feel exposed to the risk of repercussions at work¹⁸.

2.2. Policies

Policies represent the intermediate level of our pyramid because they can both influence and be influenced by the other two, practices and knowledge production. As the ultimate expression of political will, policies consist of regulatory strategies aimed at pursuing one or more objectives on behalf of the public good. The adoption of healthcare policies can result in a variety of effects on the grounds of racism and discrimination in healthcare. On the one hand, policies can directly or indirectly strengthen these phenomena. On the other, they may contribute to – or, at least, strive for – eradicating or mitigating them,

¹² L. NIMMON, T. STENFORS-HAYES, *The "Handling" of power in the physician-patient encounter: perceptions from experienced physicians*, in *BMC Medical Education*, 16, 2016, 114; J. VAN MENS-VERHULST, *Perspective of power in therapeutic relationships*, in *American Journal of Psychotherapy*, 45, 2, 1991, 198-210.

¹³ E. SUTTON, G. MARTIN, H. EBORALL, C. TARRANT, *Undertaking risk and relational work to manage vulnerability: Acute medical patients' involvement in patient safety in the NHS*, in *Social Science and Medicine*, 320, 2023, 115729; S. MATTHEWS, B. TOBIN, *Human vulnerability in medical contexts*, in *Theoretical Medicine and Bioethics*, 37, 1, 2016, 1-7.

¹⁴ T. CSORDAS, *Embodiment as a Paradigm for Anthropology*, in *Ethos*, 18, 1, 1990, 5-47.

¹⁵ About this, see B. ADHIKARI, C. AMARATUNGA, F. C. MUKUMBANG, S. R. MISHRA, *Why should we be concerned by internalised racism in global health?*, in *BMJ Global Health*, 2025, 10, 6, e016740.

¹⁶ G. WILDER, *Experiencing Racism in Health Care: Stories from Health Care Professionals*, in *Narrative Inquiry in Bioethics*, 11, 3, 2021, 231-237; A. RATTANI, *Interpersonal Racism in the Healthcare Workplace: Examining Insidious Collegial Interactions Reinforcing Structural Racism*, in *Journal of Law, Medicine and Ethics*, 49, 2, 2021, 307-314.

¹⁷ P. KAR, *Racism in the medical workforce-five initial steps*, in *British Medical Journal*, 377, 2022, o1280; NHS ENGLAND, *Medical Workforce Race Equality Standard (MWRES): WRES indicators for the medical workforce 2020*, https://www.england.nhs.uk/wp-content/uploads/2021/07/MWRES-DIGITAL-2020_FINAL.pdf (last visited 02/05/2025).

¹⁸ H. L. ABRAHIM, O. LIUSON, C. KELLEY, E. A. HOLMAN, *Racism and the well-being of nurses of color: A scoping review*, in *Nursing Outlook*, 2025, 73, 2, 102351; N. OKEAHIALAM, O. SALAMI, F. SIDDIQUI, S. THANGARATINAM, A. KHALIL, R. THAKAR, *Effects of strategies to tackle racism experienced by healthcare professionals: a systematic review*, in *BMJ Open*, 2025, 15, 1, e091811.

thus promoting inclusiveness, fairness, and citizenship. For the purposes of this work, three types of policies are identified based on their features and effects, from the more to the less discriminatory: directly discriminatory policies (DDPs), indirectly discriminatory policies (IDPs), and affirmative actions (AAs). (see Fig. no. 2). We do not consider welfare policies, whose effects could be beneficial to any population group, including racialized ones.

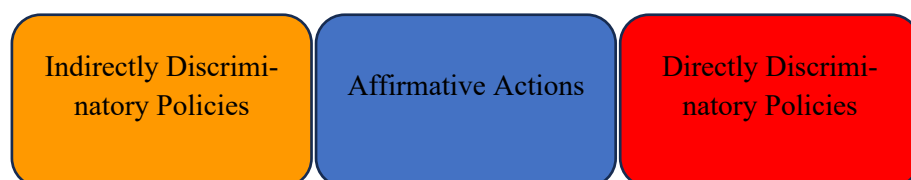


Fig. 2 – Different types of healthcare policies in relation to racism and discrimination

The deliberate aim of the DDPs is to introduce a privilege for certain people groups, leaving all the other disadvantaged. Applied in healthcare, this could occur when certain groups are conferred incentives to service access or when some others are restricted from granting access based on one or more features characterizing their group. In any case, the final result is a disparity of treatment among different population groups. As an example of this, consider the *zero tolerance* policies to the detriment of undocumented migrants that have proliferated in Europe and the US in the last 20 years¹⁹, often with severe repercussion to healthcare service accessibility for these populations. For instance, in 2009, the Italian Government approved the crime of *illegal stay* which included an obligation for healthcare professionals to report any undocumented migrants they would receive for healthcare reasons. Yet before the Constitutional Court dismantled this provision in the following years, the obligation to report undocumented migrants at the point of care was largely disregarded and strongly contested by Italian healthcare professionals as well as by many NGOs and human rights advocates that promoted *I do not report* campaigns²⁰. Similarly, in 2012, the Spanish Government approved a decree through which undocumented migrants were excluded from having access to healthcare services unless for emergency treatments. Even in this case, such a provision was openly contested for its inhuman effects, and several Spanish regions have eluded its application allowing migrants to access healthcare regardless of their legal status²¹.

More recent examples of DDPs can be found in the lack or delayed inclusion of undocumented migrants and asylum-seekers in the vaccination programs against COVID-19²². A further, outrageous example of DDPs occurred in Italy during the pandemic, when the Government rented commercial ferries to forcibly

¹⁹ T.M. GARRETT, A. SEMENTELLI, *COVID-19, asylum seekers, and migrants on the Mexico-U.S. border: Creating states of exception*, in *Politics and Policy*, 20, 2022; M. MCFADDEN, C. VELEZ, M. ÁVILA, *Pregnant Migrant Latinas at the US Border: A Reproductive Justice Informed Analysis of ICE Health Service Policy During "Zero-Tolerance"*, in *Journal of Human Rights and Social Work*, 7, 4, 2022, 349-360.

²⁰ C. BOTRUGNO, *Everyday Bioethics, Migrations, and Healthcare: Weighing the difference*, cit.

²¹ REDER, *La salud en los márgenes del sistema*, <https://www.cesida.org/wp-content/uploads/2013/09/La-salud-en-los-m%C3%A1rgenes-del-sistema.pdf> (last visited 01.10.2024).

²² A.F. CRAWSHAW, et al., *Defining the determinants of vaccine uptake and undervaccination in migrant populations in Europe to improve routine and COVID-19 vaccine uptake: a systematic review*, in *Lancet Infectious Disease*, 22, 9, 2022, e254-e266; C. BERARDI, E.S. LEE, H. WECHTLER, F. PAOLUCCI, *A vicious cycle of health (in)equity: Migrant inclusion in light of COVID-19*, in *Health, Policy and Technology*, 11, 2, 2022, 100606.

quarantine newly arrived undocumented migrants and migrants who were found to be COVID-19 positive in detention centers on Italian soil. Such a measure was highly criticized by the former Council of Europe Commissioner of Human Rights, Dunja Mijatović, as well as by NGOs and human rights advocates because of its inhuman effect but also for being epidemiologically unfounded²³.

In the case of IDPs, the prejudicial effect for some groups is created in a non-deliberate manner. This may be the case with policies that assign certain welfare benefits (such as fee reductions, exemptions, or grants to service access) to people who are residents in a determined area, or who have maintained residency for a certain period of time. The case of migrants can also be relevant here, especially considering they do not have easy access to residency in destination countries, even when their status is legal. Homeless people are another population group that can suffer from indirect discrimination in any case in which residence is taken as a criterion for conferring benefits in the social or healthcare field. The disparity created by this kind of policy may appear legitimate on a formal ground but unjustifiable from the point of view of substantial equality. This is particularly evident where the connection between the concerned requirement (e.g., residency) and the expected benefit (e.g., fee exemption) is out of scope as it exceeds any rationale for healthcare service accessibility. Color-blind policies might be seen as indirectly discriminatory insofar as they do not weigh the impact of social stratification and pretend all groups have equal opportunities. Applied to the healthcare sphere, this assumption contradicts the huge body of knowledge related to the social determinants of health and healthcare inequalities that show the existence of social gradients in health and healthcare²⁴, which means a significant disadvantage suffered by some population groups. Here, at least two main orientations can be sketched when it comes to defining the role public institutions should play in tackling disparities. On the one hand, public institutions could choose to treat all citizens *equally*, thus ignoring their socioeconomic conditions; on the other, public institutions could opt for treating their citizens *fairly*, meaning the State cannot but consider the weight of social, economic and cultural gaps that lies behind the implementation of healthcare policies.

Lastly, the AAs represent a consolidated tool – though always debated – in the fight against discrimination in all social and professional spheres. The AAs date back to the end of the U.S. Civil War, when “U.S. General William Tecumseh Sherman convinced President Abraham Lincoln to sign the “40 Acres and a Mule” bill in 1865 to support the approximately 3.9 million formerly enslaved, now freed, African

²³ S. Creta, *Italy's use of ferries to quarantine migrants comes under fire*, in *The New Humanitarian*, <https://www.thenewhumanitarian.org/news-feature/2020/11/9/italy-migration-ferries-coronavirus-quarantine-health-asylum> (last visited 1/10/2024).

²⁴ J. KARBEAH, C. R. MURRAY, C. NAKAMURA, H. BRAHMBHATT, E. CATTANEO, H. FRYE, E. SHEN, D. KAVALLERATOS, K. A. JOHNSON. *Racism in Pediatric Serious Illness and Palliative Care: A Scoping Review of Qualitative Research*, in *Journal of Pain Symptom Management*, 2025, 69, 1, 44-52; M. A. BELDON, S. L. CLAY, S. D. UHR, C. L. WOOLFOLK, I. J. CANTON. *Exposure to Racism and Adverse Pregnancy Outcomes for Black Women: A Systematic Review and Meta-Analysis*, in *Journal of Immigrant and Minority Health*, 2025, 27, 1, 149-170; N.K. COTTON, R.S. SHIM, *Social Determinants of Health, Structural Racism, and the Impact on Child and Adolescent Mental Health*, in *Journal of American Academy of Child and Adolescent Psychiatry*, 61, 11, 2022, 1385-1389; O. BERRY, A. LONDOÑO TOBÓN, W. NJORGE, *Social Determinants of Health: The Impact of Racism on Early Childhood Mental Health*, in *Current Psychiatry Report*, 23, 5, 2021, 23; L. EGEDE, R. WALKER, J. WILLIAMS, *Intersection of Structural Racism, Social Determinants of Health, and Implicit Bias With Emergency Physician Admission Tendencies*, *JAMA Network Open*, 4, 9, 2021, e2126375; F. RAMOS-GOMEZ, J. Kinsler, *Addressing social determinants of oral health, structural racism and discrimination and intersectionality among immigrant and non-English speaking Hispanics in the United States*, in *J Public Health Dentistry*, 82, Suppl 1, 2022, 133-139.

Americans from the South” to achieve economic independence and wellbeing throughout their own work²⁵. The core of the AAs is the recognition of the factors of disadvantage and inequality that affect some groups which justifies the adoption of specific policies aimed at compensating this imbalance. A preferential strategy to achieve this goal is the establishment of quotas, or else the destination of a number of positions to members belonging to racialized (or other disadvantaged) groups. In healthcare, AAs can result from the adoption of waiver mechanisms or of target programs aimed to strengthen service accessibility for some people groups. The COVID-19 pandemic has provided an abnormous scenario of inequality and social injustice that has triggered specific considerations related to the applicability of AAs in healthcare. In this regard, a *weak* and a *strong* perspective for AAs in healthcare have been identified²⁶. The first refers to the allocation of “scarce resources that seeks to provide strictly equal chances of allocation by encouraging participation of the disadvantaged racial group and seeking to reduce risk of bias in selection among those who are (roughly) equally qualified for allocation”²⁷. The second, consists of a policy which aims at “allocating scarce resources to a disadvantaged racial group”²⁸. If a weak AAs perspective would be limited to e.g., introducing arrangements that meet the needs of a particular group with a view to enhancing their access, a strong AAs perspective would rather give priority access to members of the racialized (or disadvantaged) group in the allocation of scarce resources – a situation that is predominant in the healthcare field.

2.3. Knowledge

When talking about the production of knowledge, I refer to a non-essentialist and non-deterministic perspective, thus rejecting the Socratic vision of knowledge as something that pre-exists and that humans simply *discover*. Conversely, knowledge is here treated as a *cultural product*²⁹ or else the ultimate outcome of a social process, shaped by a series of actors, material and non-material factors, institutions and procedures socially recognized as legitimate sources of knowledge production³⁰. This perspective enshrines the analysis of *race* as an epistemic notion and a category commonly used in both biomedical and nonbiomedical sciences.

²⁵ D. NARDI, *Affirmative Action in the United States: History and Future*, in *Journal of Psychosocial Nursing and Mental Health Services*, 62, 1, 2024, 3-5.

²⁶ H. ZOHNY, B. DAVIES, D. WILKINSON, *Affirmative action in healthcare resource allocation: Vaccines, ventilators and race*, in *Bioethics*, 36, 9, 2022, 970-977.

²⁷ *Ibid.*

²⁸ *Ibid.*

²⁹ D. BLOOR, *Knowledge and social imagery*, London, 1976. B. LATOUR, *Laboratory life: The construction of scientific facts*, Princeton, NJ, 1986; W. SEWELL, *The concept(s) of culture*, in V.E. Bonnell, L. Hunt (eds), *Beyond the cultural turn: of society and culture*, 35-61, Berkeley, 1999; S. SHAPIN, *Discipline and bounding: The history and sociology of externalism-internalism debate*, in *History of Science*, 30, 1992, 333-369; S. SHAPIN, S. SCHAFER, *Leviathan and the air-pump: Hobbes, Boyle and the experimental life*, Princeton, NJ, 1995.

³⁰ A. PICKERING, *From science as knowledge to science as practice*, In A. Pickering (ed), *Science as practice and culture*, 1-26, Chicago, 1992.

Discussion about the existence and the usefulness of race is not new³¹, although recently a bigger awareness has permeated the debate in the medical and bioethics fields. The discourse about race is so articulated that it has been described in terms of *metaphysics*³². The latter would include three different views: racial skepticism, racial constructionism, and racial naturalism³³. Racial naturalism was predominant until a few decades ago, and it is based on the assumption that human populations can naturally be grouped into distinct races whose members have bio-behavioral traits in common. Racial constructionists differ in that they reject any predetermined human classification but – to some extent – agree, accept, or find useful the existence of socially constructed groups of humans referred to as races. Racial skeptics, conversely, argue that races do not exist at all, a view that has become widely shared among racial theorists, taking to a sort of *ontological consensus*³⁴.

Talking about the meaningfulness of race as a notion, a huge and transversal body of literature, including a number of guidelines and statements, has already acknowledged that race is a social construct³⁵. From a constructionist perspective, race is seen as “a socially assigned identity that only partly reveals scientific information about a person. It is not a reliable proxy for biological difference, and as global admixture increases, the reliability of categorizing people by self-reported or perceived race wanes”³⁶. By contrast, a skeptical position is the one expressed within the “Statement on Race” adopted by the American Association of Physical Anthropologists (AAPA)³⁷, which underscores that “Race does not provide an accurate representation of human biological variation. It was never accurate in the past, and it remains inaccurate when referencing contemporary human populations”³⁸.

Beyond the value of the abstract categories, the discussion about the heuristic value and the usefulness of race and its derivatives as population descriptors in biomedical research remains complex and reveals many contradictions and inconsistencies, particularly when it comes to connecting racially-derived groups with the knowledge emerging from the mapping of the human genome.

³¹ T. SHELDON, H. PARKER, *Race and ethnicity in health research*, in *Journal of Public Health and Medicine*, 14, 1992, 104-110; K.J. McKenzie, N. Crowcroft, *Race, Ethnicity, Culture, And Science: Researchers Should Understand and Justify Their Use Of Ethnic Groupings*, in *British Medical Journal*, 309, 6950, 1994, 286-287.

³² R. MALLON, “Race”: Normative, Not Metaphysical or Semantic, in *Ethics*, 116, 2006, 525-551.

³³ *Ibid.*

³⁴ *Ibid.*

³⁵ C. BOTRUGNO et al. 2023, op. cit.; G. ADIGBLI, *Race, science and (im)precision medicine*, in *Nature Medicine*, 26, 11, 2020, 1675-1676; A. FLANAGIN, T. FREY, S. CHRISTIANSEN, *AMA Manual of Style Committee. Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals*, in *Journal of American Medical Association*, 326, 7, 2021, 621-627; M. CHO, M. DUQUE LASIO, I. AMARILLO, K. MINTZ, R. BENNETT, K. BROTHERS, *Words matter: The language of difference in human genetics*, in *Genetics Medicine*, 25, 3, 2023, 100343; K.N. MAGLO, T.B. MERSHA, L. MARTIN, *Population Genomics and the Statistical Values of Race: An Interdisciplinary Perspective on the Biological Classification of Human Populations and Implications for Clinical Genetic Epidemiological Research*, in *Frontier Genetics*, 7, 2016, 22; J.K. MALINOWSKA, D. SERPICO, *Epistemological Pitfalls in the Proxy Theory of Race: The Case of Genomics-Based Medicine*, in *British Journal for the Philosophy of Science*, 2024, Ahead of print <https://doi.org/10.1086/727957>; F.S. COLLINS, *What we do and don't know about 'race', 'ethnicity', genetics and health at the dawn of the genome era*, in *Nature Genetics*, 36, 11 Suppl, 2004, S13-S15; M. UDLER, et al., *Effect of Genetic African Ancestry on eGFR and Kidney Disease*, in *Journal of American Society of Nephrology*, 26, 7, 2015, 1682-1692.

³⁶ G. ADIGBLI, op. cit.

³⁷ A. FUENTES, et al., *AAPA Statement on Race and Racism*, in *American Journal of Physical Anthropology*, 169, 3, 2019, 400-402.

³⁸ *Ibid.*, 9.

2.3.1. The *discreet charm* of race in genetics and genomics

Building on the work of the U.S. geneticist Richard Lewontin³⁹, a huge scholarship has acknowledged that a higher genetic variation can be found in racial grouping instead of between them⁴⁰. Contemporary geneticists have shown to be aware that the value of race in genetics is “tenuous”⁴¹ given that genetic variations between races do not own a meaningful attribute⁴². Consistently with the acknowledgment that race is a social construct, geneticists indeed emphasize the lack of any correspondence between genetic clusters and the racial classification of humans⁴³. Such an orientation, however, is shared transversally, as clearly expressed by the AAPA Statement⁴⁴, which underlines that “Humans are not divided biologically into distinct continental types or racial genetic clusters. Humans share the vast majority (99.9%) of our DNA in common. Individuals nevertheless exhibit substantial genetic and phenotypic variability. Genome/environment interactions, local and regional biological changes through time, and genetic exchange among populations have produced the biological diversity we see in humans today. Notably, variants are not distributed across our species in a manner that maps clearly onto socially recognized racial groups. This is true even for aspects of human variation that we frequently emphasize in discussions of race, such as facial features, skin color, and hair type. No group of people is, or ever has been, biologically homogeneous or ‘pure.’ Furthermore, human populations are not—and never have been—biologically discrete, truly isolated, or fixed”⁴⁵.

Even ancestry, or “a person’s country or region of origin or an individual’s lineage of descent”⁴⁶, which is commonly thought to be a more accurate predictor for genetic variation and risk for disease or disorder than ethnicity and race⁴⁷ does not seem to be completely reliable due to the increasing genetic admixture or genetic make-up⁴⁸. Regarding ancestry, it has been argued that even tackling the issue of genetic admixture computationally, i.e., identifying continental ancestry through large dimensional genomic data, “does not necessarily imply that race as defined by continental ancestry is meaningful in biological systematics and evolutionary classification. In fact, the genomic and statistical evidence currently available

³⁹ R. LEWONTIN, *The Apportionment of Human Diversity*, in T. Dobzhansky, M.K. Hecht, W.C. Steere (eds), *Evolutionary Biology*, 381-398, New York, 1972.

⁴⁰ G. ADIGLBI, op. cit.; D. WITHERSPOON, et al., *Genetic similarities within and between human populations*, in *Genetics*, 176, 1, 2007, 351-359. Y. ROMAN, *Race and precision medicine: is it time for an upgrade?*, in *Pharmacogenomics Journal*, 19, 1, 2019, 1-4; S. MACEachern, *The concept of race in contemporary anthropology*, in R. SCUPIN (ed), *Race and Ethnicity: The United States and the World*, 34-57, Upper Saddle River, NJ, 2019. L. JORDE, S. WOODING, *Genetic variation, classification and ‘race’*, in *Nature Genetics*, 36, 11 Suppl, 2004, S28-S33.

⁴¹ G. ADIGLBI, op. cit.

⁴² A. RUTHERFORD, *How to Argue With a Racist: What Our Genes Do (and Don't) Say About Human Difference*, New York, 2020.

⁴³ M. CHO, et al., op. cit.; K.N. MAGLO et al., op. cit.

⁴⁴ A. FUENTES, et al., op. cit.

⁴⁵ *Ibid.*, 9.

⁴⁶ A. FLANAGIN et al., op. cit.

⁴⁷ *Ibid.*, 622.

⁴⁸ S.N. MUNUNG, *Ethnicity, Geographical Region and Ancestry as Population Level Descriptors for Genomics Studies in Africa: Public Engagement is Needed*. In C. BOTRUGNO, M. M. RAYMUNDO, L. RE, *Bioethics and racism: Practices, conflicts, negotiations and struggles*, Berlin, 2023.



shows that phylogenetic and genetic similarity-based concepts of race fail to be applicable to humans even under minimal rational theoretical principles currently accepted in population genetics/genomics⁴⁹. If race or ethnicity is not responsible for human variation, and ancestry represents a piece of feeble information, the identification of the factors from which differences between people groups may depend becomes crucial. The prejudicial view that racial grouping can be clinically or genetically meaningful is now challenged by evidence showing that geographical origin can be a better proxy for building human taxonomy than race⁵⁰. In this regard, it has been argued that “geography has historically been the greatest predictor of genetic variation between human populations, with genetic distance increasing as geographic distance increases”⁵¹. Based on this, demo-geographical grouping that leverages the seven geographically-defined clusters (i.e., American, Central/South Asian, East Asian, European, Near Eastern, Oceanian, and Sub-Saharan African, and two admixed groups of African American/Afro-Caribbean and Latino) would be much more accurate than any race and ethnicity-based classification. However, even these clusters would still be considered “idealizations and generalizations”⁵².

The relevance of geography as a proxy for the study of human variability can be further detailed in relation to the features of the ecological environments inhabited by humans⁵³. On the one hand, inhabiting certain climates and surviving their changes would have shaped biological and cultural evolution by means of adaptation. On the other, they would have determined or, in some cases, forced humans to migrate to find easier conditions for survival⁵⁴. Human migrations are therefore responsible to a significant extent for the mix-up in the genetic pool of the *homo sapiens*⁵⁵. This is not only true when considering human movement flows in prehistory or ancient history. Even today, eco-environmental factors combined with migration flows shape the phylogenetics of populations, thus making it “harder to use any demo-geographical classifications efficiently in genetics or pharmacogenomics” but also making any “realist, biologically and essentialist interpretations of the category of race completely inadequate and useless when applied to humans”⁵⁶.

In parallel to this, scholars increasingly emphasize the role played by societal factors even at the genetic level⁵⁷, thus contributing to dismantling not just the correspondence between racial classification and genetic clusters but the same idea that the DNA can be considered alone as a predictor of health or

⁴⁹ K.N. MAGLO, et al., cit., 10.

⁵⁰ R. HUDDART et al., *Standardized Biogeographic Grouping System for Annotating Populations in Pharmacogenetic Research*, in *Clinical Pharmacology and Therapeutics*, 105, 2019, 1256-1262.

⁵¹ *Ibid.*, 1258.

⁵² J.K. MALINOWSKA, T. ŻURADZKI, *Towards the multileveled and processual conceptualisation of racialised individuals in biomedical research*, in *Synthese*, 201, 1, 2023, 11.

⁵³ F. MAUELSHAGEN, *Migration and climate in world history*. In S. White, C. Pfister, F. Mauelshagen (eds), *The Palgrave handbook of climate history*, 413-444, London, 2018.

⁵⁴ J.K. MALINOWSKA, T. ŻURADZKI, op. cit., 10.

⁵⁵ P.D. CURTIN, *Africa and global patterns of migration*, in W. GUNGWU, *Global history and migrations*, 63-94, London, 2018; P. MANNING, T. TRIMMER, *Migration in world history*, London, 2020; C. SCHLEBUSCH, M. JAKOBSSON, *Tales of human migration, admixture, and selection in Africa*, in *Annual Review of Genomics and Human Genetics*, 19, 2018, 405-428.

⁵⁶ J.K. MALINOWSKA, T. ŻURADZKI, op. cit., 11.

⁵⁷ *Ibid.*

disease⁵⁸. For instance, adversity has been deemed to be predictive of “heritable epigenetic modifications commensurate with health outcomes”⁵⁹. This would entail that DNA absorbs and transmits stress and traumas suffered from the ancestors⁶⁰.

Despite this, race and its derivatives still exert a *discreet charm* especially in genetics and genomics⁶¹. Indeed, it is commonly thought that gene variants can be predictive of heritable risk despite this having been deemed as infrequent⁶². A possible explanation for this is identified by Malinowska and Serpico⁶³ in the critics moved by Edwards⁶⁴ to the so-called “Lewontin’s fallacy”. In other words, Edwards underscored that “most of the information that distinguishes populations is hidden in the correlation structure of the data and not simply in the variation of the individual factors”⁶⁵. From this perspective, correlations among genetic loci would confer meaningfulness to racial categorizations of humans. To show the wide acceptance of this idea, Malinowska and Serpico⁶⁶ recall a statement by the American Society of Human Genetics⁶⁷ issued with the main aim of stigmatizing any attempts to connect genetics to racial supremacy. On the one hand, the Statement clearly acknowledges that “The study of human genetics challenges the traditional concept of different races of humans as biologically separate and distinct” and it continues “Most human genetic variation is distributed as a gradient, so distinct boundaries between population groups cannot be accurately assigned”⁶⁸. From this perspective, the idea of racial purity passes to be “scientifically meaningless”⁶⁹. However, the same Statement recognizes the existence of a correlational structure among race-based groups, i.e., “Although there are clear observable correlations between variation in the human genome and how individuals identify by race, the study of human genetics challenges the traditional concept of different races of humans as biologically separate and distinct”⁷⁰.

⁵⁸ N. SNYDER-MACKLER, et al., *Social determinants of health and survival in humans and other animals*, in *Science*, 368 6493, 2020.

⁵⁹ G. ADIGBLI, op. cit.

⁶⁰ T.W. MCDADE, et al. *Genome-wide analysis of DNA methylation in relation to socioeconomic status during development and early adulthood*, in *American Journal of Physical Anthropology*, 169, 1, 2019, 3-11; J. WRIGHT, J. JARVIS, L. PACTHER, L.M., R. WALKER-HARDING, *Racism as a public health issue*, in *Pediatric Research*, 88, 5, 2020, 696-698; D. COSTA, N. YETTER, H. DESOMER, *Intergenerational transmission of paternal trauma among US Civil War ex-POWs*, in *Proceedings of the National Academy of Science*, 115, 44, 2018, 11215-11220.

⁶¹ C. BOTRUGNO, *The racial epistemicide of bioethics*, in C. BOTRUGNO, M. RAYMUNDO, L. RE, *Bioethics and racism: Practices, conflicts, negotiations and struggles*, cit.

⁶² O. ZUK, E. HECHTER, S. SUNYAEV, E. LANDER, *The mystery of missing heritability: Genetic interactions create phantom heritability*, in *Proceedings of the National Academy of Science*, 109, 4, 2012, 1193-1198; U. MARIGORTA, J. RODRÍGUEZ, G. GIBSON, A. NAVARRO, *Replicability and Prediction: Lessons and Challenges from GWAS*, in *Trends in Genetics*, 34, 7, 2018, 504-517.

⁶³ J.K. MALINOWSKA, D. SERPICO, op. cit.

⁶⁴ A. EDWARDS, *Human Genetic Diversity: Lewontin’s Fallacy*, in *BioEssays*, 25, 2003, 798-801.

⁶⁵ *Ibid.*, 798.

⁶⁶ J.K. MALINOWSKA, D. SERPICO, op. cit.

⁶⁷ AMERICAN SOCIETY OF HUMAN GENETICS, *ASHG Denounces Attempts to Link Genetics and Racial Supremacy*, in *American Journal of Human Genetics*, 103, 5, 2018, 636.

⁶⁸ *Ibid.*, 636.

⁶⁹ *Ibid.*

⁷⁰ *Ibid.*

A similar contradiction can be found in Adigbli⁷¹, who, on the one hand, underscores a main risk intrinsic to the use of racial categories, which is the “fixation on average inter-population disparities” that can lead researchers to “underappreciate inter-individual heterogeneity and under-study potential explanations for the racial differences they identify”⁷². On the other, he also argues that “Despite the paucity of evidence for forward genetic linkage, biomedical exploration of racial difference is not without merit. Valuable mechanistic pathways in disease etiology and treatment response have been identified through such exploration, and descriptive statistics of grouped populations are valuable in epidemiological analyses”⁷³. Another example of this inconsistency can be found in the “Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals”⁷⁴ adopted by the Journal of American Medical Association (JAMA). Such guidance clearly emphasizes that race is a social construct and alerts us to the risk of relying on racial classifications. The Guidance indeed clarifies that any associations between health outcomes and race or ethnicity may be too simplistic given that these outcomes “may also be intertwined with ancestry and heritage, social determinants of health, as well as socioeconomic, structural, institutional, cultural, demographic, or other factors”⁷⁵. Despite this, the JAMA Guidance legitimizes in some way the use of race and its derivatives as population descriptors if surrounded by some “precautions” such as integrating those descriptors with other factors or preferring genetic admixture and ancestry to race and ethnicity. In this way, they contribute to giving them a “biological overtone”⁷⁶, which unfolds the risk of biasing diagnostic process and treatment guidelines, thus paving the way for the so-called “race-tailored” medicine⁷⁷.

2.3.3. Race-tailored medicine

Biomedical research is plenty of cases where race has been used as a proxy for the study of human variability⁷⁸. This undermines the scientific accuracy that supposedly guides both the production of evidence, but also clinical judgment and diagnostic process. As it has been emphasized, racial biases in medicine expose racialized patients to stereotypes and folk medical beliefs⁷⁹. Roman⁸⁰ reports several race-tailored FDA-approved drugs, which include the use of angiotensin-converting enzyme inhibitors that “was long

⁷¹ G. ADIGBLI, op. cit.

⁷² *Ibid.*

⁷³ *Ibid.*

⁷⁴ A. FLANAGIN et al. op. cit.

⁷⁵ *Ibid.*, 622.

⁷⁶ J.K. MALINOWSKA, T. ŻURADZKI, op. cit.

⁷⁷ Y. ROMAN, cit.

⁷⁸ D. KHANNA, et al., *2012 American College of Rheumatology guidelines for management of gout. Part 1: systematic nonpharmacologic and pharmacologic therapeutic approaches to hyperuricemia*, in *Arthritis Care Research*, 64, 2012, 1431-1446; N. STONE, et al., *2013 ACC/AHA guideline on the treatment of blood cholesterol to reduce atherosclerotic cardiovascular risk in adults: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines*, in *Journal of American College of Cardiology*, 63, 25, 2014, 2889-2934; P.A. JAMES, et al., *Evidence-based guideline for the management of high blood pressure in adults: report from the panel members appointed to the Eighth Joint National Committee (JNC 8)*, in *Journal of American Medical Association*, 311, 2014, 507-520.

⁷⁹ J.K. MALINOWSKA, T. ŻURADZKI, op. cit., 17.

⁸⁰ Y. ROMAN, op. cit.

believed to be ineffective in blacks due to reduced circulating levels of plasma renin relative to other racial groups”⁸¹. This racial bias led to “a race-based guideline recommendation for the management of hypertension in Blacks vs. Non-Blacks”⁸². A further paradigmatic example of race-tailored medicine comes from the *BiDil* or else the combination of isosorbide and hydralazine, a drug approved by the FDA to treat heart failure in a particular population group, African American and thus became “the first race-based approved drug in the US”⁸³.

A further example concerns “the guidelines for the management of blood cholesterol in adults warrant initiating a lower dose of rosuvastatin in Asian-descent patient population than their other population counterparts due to the increased risk of myopathy”⁸⁴, or the guidelines adopted by the American College of Rheumatology which “caution about the use of allopurinol in certain Asian sub-population groups due to the increased risk of developing Stevens–Johnson Syndrome”⁸⁵.

The essentialization of race endangers the risk of acting as a confounding factor. A clear example of this comes from the comparison of the obesity rate between African American and Whites American, with the first group reporting higher rates of obesity than the latter⁸⁶. Such a difference in the obesity risk between the two groups, however, could be due to many other non-biological factors “including local environment and availability of healthy food options and cultural food preferences. Indeed, in Africa the rates of obesity are much lower than what is reported in African Americans in the US”⁸⁷.

The above examples show how the rigid fixation of the features of a racialized group turned out to be a bias for clinical accuracy. The mechanisms intrinsic to the scientific legitimization of racial biases evoke the *self-fulfilling prophecy*, a mechanism that is further explained by the famous quote from Thomas and Thomas⁸⁸, “If men define situations as real, they are real in their consequences”. In other words, the effort to seek a *difference* in the (racialized) body can be so *blind* that it ends up creating that difference, or at least it contributes to widening its magnitude. Over time, the use of race as a reference for the development of new targeted drugs has indeed legitimized “the existence of biological differences between ‘races’ and inspired many companies and researchers to study these differences intensively”⁸⁹, thus contributing to the development of a sort of *race marketing*.

2.3.4. The standards

Despite the seemingly large consensus about race and its derivatives as social constructs, they acquired impressive power in the health sciences and medical knowledge. Among the other, they are “commonly

⁸¹ *Ibid.*

⁸² *Ibid.*

⁸³ *Ibid.*

⁸⁴ *Ibid.*

⁸⁵ *Ibid.*

⁸⁶ C. ROMERO, T. ROMERO, J. SHLAY, L. OGDEN, D. DABELEA, *Changing trends in the prevalence and disparities of obesity and other cardiovascular disease risk factors in three racial/ethnic groups of USA adults*, in *Advances in Preventive Medicine*, 2012, 172423; C. OGDEN, et al., *Prevalence of obesity and trends in body mass index among US children and adolescents, 1999-2010*, in *Journal of American Medical Association*, 307, 483-490.

⁸⁷ K.N. MAGLO et al., op. cit. 9.

⁸⁸ W.I. THOMAS, D. THOMAS. *The child in America: Behavior problems and programs*, New York, 1928.

⁸⁹ J.K. MALINOWSKA, D. SERPICO 2024, op. cit.



applied as a reference class in randomised control trials (RCTs), polygenic risk scores (PRS) or diagnostic algorithms⁹⁰. This is particularly true in the US, where the National Institutes of Health has required the collection of race and ethnicity for clinical trial submission since 2001⁹¹. In 2016, the FDA adopted its own “Guidance for Industry and Food and Drug Administration Staff on Collection of Race and Ethnicity Data in Clinical Trials”⁹² where researchers are called to refer to the following racial categories: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian and Other Pacific Islander and White, integrated by two ethnic categories: Hispanic or Latino and Not Hispanic or Latino⁹³. In Europe, despite the use of races as population descriptors being relatively infrequent compared to the U.S., there is evidence of increasing use in reporting racial data in EU pharmacological studies⁹⁴.

As seen before, in parallel with the public authorities’ guidelines and orientations, influential journals have adopted their guidance documents on the collection of race and ethnicity data⁹⁵. The proliferation of these guidelines as *tools* for racial data collection appears problematic not only because it adds to the provisions of policy documents already adopted by health authorities, but also because it generates conflicting or divergent orientations on *if*, *when*, and *how* collecting and reporting those data. This must be coupled with the general uncertainty and confusion reported in the scholarship committed to working alongside the study of difference and human variability in healthcare and medicine⁹⁶. As has been highlighted in this regard⁹⁷, while in some cases the ethnic categories are used in parallel to the racial clusters, in some others they are presented as equivalent or even interchangeable. Confusion about the notions of race, ethnicity, and ancestry is not merely about their use but also about their interpretation. Even geneticists have shown to be unable to clearly define and thus distinguish the notions of race, ethnicity, and ancestry⁹⁸. Moreover, the use of these categories has been found to depend on several contextual factors, such as researchers’ objectives, datasets available, sociocultural environments in which they operate⁹⁹. In

⁹⁰ J.K. MALINOWSKA, T. ŻURADZKI, *op. cit.*

⁹¹ NATIONAL INSTITUTES OF HEALTH, *Inclusion of Women and Minorities as Participants in Research Involving Human Subjects*, 2001, <https://grants.nih.gov/policy-and-compliance/policy-topics/inclusion/women-and-minorities> (last visited: 02/05/2025).

⁹² FOOD AND DRUG ADMINISTRATION, *Food and Drug Administration Guidance for Industry and Food and Drug Administration Staff on Collection of Race and Ethnicity Data in Clinical Trials*, 2016, <https://www.fda.gov/regulatoryinformation/search-fda-guidance-documents/collection-race-and-ethnicity-data-clinical-trials> (last visited: 02/05/2025).

⁹³ *Ibid.*

⁹⁴ S. MULINARI, A. VILHELMSSON, P. OZIERANSKI, A. BREDSTRÖM, *Is There Evidence for the Racialization of Pharmaceutical Regulation? Systematic Comparison of New Drugs Approved over Five Years in the USA and the EU*, in *Social Science and Medicine*, 280, 2021.

⁹⁵ A. FLANAGIN et al., *op. cit.*; B. ZIKMUND-FISHER, *Toward Transparent Demographic Analyses: Statement on the Use and Reporting of Classification Variables Presented as Measuring Individual Characteristics Such as Race, Ethnicity, Indigeneity, National Origin, Gender, Sexual Orientation, or Socioeconomic Status*, in *Medical Decision Making*, 42, 3, 2022, 277-279.

⁹⁶ J.K. MALINOWSKA, D. SERPICO, *op. cit.*; M. MAURO, et al., *A scoping review of guidelines for the use of race, ethnicity, and ancestry reveals widespread consensus but also points of ongoing disagreement*, in *American Journal of Human Genetics*, 109, 12, 2022, 2110-2125; A. POPEJOY, et al., *Clinical Genetics Lacks Standard Definitions and Protocols for the Collection and Use of Diversity Measures*, in *The American Journal of Human Genetics*, 107, 2020, 72-82.

⁹⁷ J.K. MALINOWSKA, D. SERPICO, *op. cit.*

⁹⁸ A. POPEJOY, et al., *op. cit.*

⁹⁹ R. HUDDART et al., *op. cit.*; M. LÓPEZ, M. BEVANS, L. WEHRLIN, L. YANG, G.R. WALLIN, *Discrepancies in Race and Ethnicity Documentation: A Potential Barrier in Identifying Racial and Ethnic Disparities*, in *Journal of Racial and Ethnic Health*

a recent scope review assessing the normative recommendations on the racial and ethnic data report, it has been found that scholars expressed a high range of different orientations about the acceptability of racial data collection¹⁰⁰. While some have argued that using racial-informed population descriptors is always acceptable, others have found their use to be acceptable only to certain conditions, and some others declared that it is never acceptable¹⁰¹. As the authors concluded, “The considerable disagreement amongst these recommendations indicates that a lack of clear, centralized definitions of population categories goes hand in hand with confusion and disagreement about when they should be used”¹⁰². This lack of uniformity not only proves the frailty of these categories from an epistemic level but also shows how these population descriptors can undermine clinical accuracy, with severe repercussions on the reliability of collected evidence.

A further issue concerning the collection of racial data comes from the circumstance that the assignation of individuals to a certain racial or ethnic group is mostly based on self-declaration¹⁰³. This proves that the collection of racial data turns into a “moving target problem”¹⁰⁴. Indeed, “racial categorization is not only faced with the challenge of distinct biological differences but also the self-perception of race and social identity of these individuals. This race self-identification could be based on a belief system or select cultural norms of the individual, which might be in discordance to the person’s actual or biological race. Moreover, the predetermined racial categorization list approach may undermine the diversity and the presence of distinct subgroups that exist within the same race”¹⁰⁵. As is observable, this (constructionist) view leaves room for the existence of different races (and racial subgroups). In such a perspective, the moving target problem would be worsened by the increasing global admixture¹⁰⁶. Conversely, in other cases, race and its derivatives are treated as a *pure* social construct, i.e., they are used as population descriptors despite the premise that races do not exist at all. This is the case of the Brazilian National Strategy for the Integral Health Protection of Black Population¹⁰⁷. Such a policy, adopted within the Brazilian NHS, aims at collecting race and color features of people accessing care services across the NHS. Analyzing the disadvantages suffered by racialized groups all over the country is meant as a base for future actions and measures aimed at compensating healthcare inequalities. From a theoretical perspective, one can argue that this use of racial categories is unproblematic as it only aims at collecting data related to service accessibility and discrimination. However, the risk intrinsic to this kind of policy comes from the

Disparities 4, 2017, 812-818; F. ZHANG, J. FINKELSTEIN, *Inconsistency in Race and Ethnic Classification in Pharmacogenetics Studies and Its Potential Clinical Implications in Pharmacogenomics and Personalized Medicine*, 12, 2019, 107.

¹⁰⁰ M. MAURO et al., op. cit.

¹⁰¹ *Ibid.*

¹⁰² *Ibid.*, 2120.

¹⁰³ Y. ROMAN, op. cit.; NHS Brazil, *Política Nacional de Saúde Integral da População Negra: uma política do SUS*, 2010, https://bvsms.saude.gov.br/bvs/publicacoes/politica_saude_integral_populacao_negra.pdf (last visited: 02/05/2025); NHS BRAZIL, *Política Nacional de Saúde Integral da População Negra: uma política do SUS*, 2017 https://www.gov.br/saude/pt-br/composicao/saps/equidade/publicacoes/populacao-negra/politica_nacional_saude_populacao_negra_3d.pdf (last visited: 02/05/2025).

¹⁰⁴ Y. ROMAN 2019, op. cit.

¹⁰⁵ *Ibid.*, 2.

¹⁰⁶ *Ibid.*

¹⁰⁷ NHS BRAZIL, *Política Nacional de Saúde Integral da População Negra: uma política do SUS*, op. cit.; NHS BRAZIL, *Política Nacional de Saúde Integral da População Negra: uma política do SUS*, op. cit.

circumstance that racial constructionism often intersects – implicitly or explicitly – racial naturalism or the belief that something at the biological or genetic level differentiates inter-group variability. In other words, the main drawback of leveraging race and its derivatives as population descriptors lies in the fact that it contributes somehow to the *biologization of the social* (Fig. no. 3). Although aiming to mitigate racism and discrimination, this process acts as a vicious cycle that risks to reifying – better saying, biologizing – race and its derivatives, thus contributing to further social injustice, abuse, discrimination, and racism.

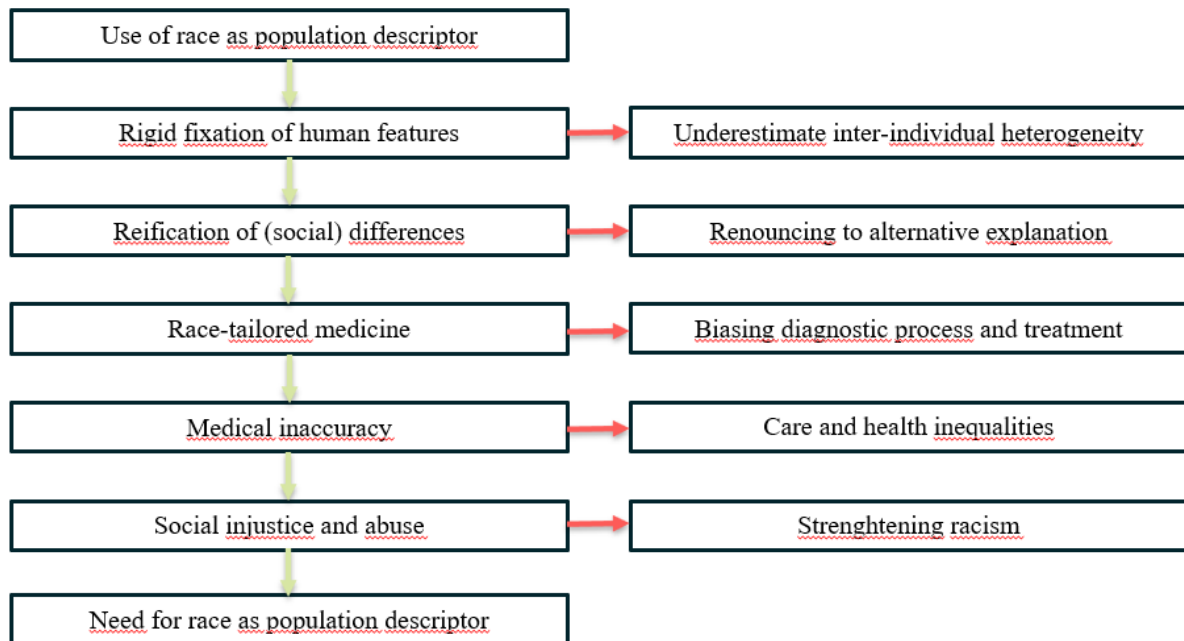


Fig. 3 – The *biologization of the social* as a process.

In brief, the use of population descriptors in biomedical research leads to a rigid fixation of the human features, which has as a side effect an underestimation of individual heterogeneity. A rigid fixation of the human features, in turn, causes a reification of the social difference(s) between humans, which takes to renounce alternative, non-biologicistic explanations. As already seen, the reification of the social difference(s) legitimates the so-called race-tailored medicine and the run toward the development of new race-targeted drugs, which contributes to reinforcing biases in diagnostics and treatment to the detriment of racialized groups. Race-tailored medicine affects medical accuracy, paving the way to further healthcare inequalities. The lack of accuracy in medicine increases social injustice and abuse, which strengthens racism and discrimination. Paradoxically, fighting against racism and discrimination induces scholars to make further affordance on race-based population descriptors in biomedical research, which unavoidably contributes to giving a biological overtone to race.

3. What role for bioethics?

3.1. Practices

As underscored above, I consider medical knowledge from a non-essentialist and non-deterministic vision, or else as a socio-cultural product. Evidence shows¹⁰⁸ that medical knowledge is formed and transmitted in collective forms, according to socially accepted procedures, which involve the socialization of young professionals to that array of practices that contribute to the emergence of knowledge in the healthcare system. This perspective sheds light on racism and discrimination in healthcare given that racist practices – like any others –, are inevitably grafted onto a socio-cultural background. In other words, racist practices are strictly tied to the socialization process that takes clinicians to learn, emulate, share, and replicate attitudes, orientations, beliefs, values, and norms. Bioethics has the power to break this chain if it can have room both in the clinical settings, where bioethics is implemented, as well as in the medical and nursing courses, where future professionals move their first steps into the system¹⁰⁹. Of course, this can be useful only if bioethicists have the tools to recognize racial and discrimination issues and to react to them following the best of the knowledge available in this field. For this purpose, bioethics scholars must commit themselves to rethink their categories, put in discussion their identity, and question the practices, views, and theories they have learned and have been socialized to throughout their education path and their careers (section 3.3.).

Concerning the clinical setting, the presence of bioethics is pivotal to stimulating a higher awareness among all healthcare professionals about racial and discrimination issues. Clinical ethics committees can have a main role here, provided that their composition guarantees the presence of members who belong to racialized groups or, at least, are experts in racism and discrimination issues. In parallel, another solution is creating ad hoc committees for racial and discrimination issues, which can intervene whenever such situations need to be addressed¹¹⁰.

¹⁰⁸ P. ATKINSON, *Medical talk and medical work*, London, 1995; P. ATKINSON, *Medical discourse, evidentiality and the construction of personal responsibility*, in S. SARANGI, S. ROBERTS (eds), *Talk, work and institutional order. Discourse in medical, mediation and management settings*, 75-107, Berlin, 1999; A. CICOUREL, *The interpenetration of communicative contexts: examples from medical encounters*, in *Social Psychology Quarterly*, 50, 2, 1987, 217-226; A. CICOUREL, *The Integration of Distributed Knowledge in Collaborative Medical Diagnosis*, in J. GALEGHER, R.E. KRAUT, C. EGIDO (eds), *Intellectual Teamwork. Social and Technological Foundations of Cooperative Work*, 221-242, New York, 1990; A. CICOUREL, *Hearing is not believing: language and the structure in medical belief*, in A. TODD, S. FISHER (eds), *The social organization of doctor-patient communication*, 221-239, Washington, 1993.

¹⁰⁹ A recent review highlights the increasing demand for teachers to promote anti-racist education in healthcare; see D. D. BINDA, A. KRAUS, L. GARIÉPY-ASSAL, B. TANG, C. G. WADE, D. D. OLVECZKY, R. MOLINA. *Anti-racism curricula in undergraduate medical education: A scoping review*, in *Medical Teaching*, 2025, 47, 1, 99-109.

¹¹⁰ As example of this, see the Ethnic and Racial Issues Committee of the Society for Research in Child Development, available at <https://www.srcd.org/about-us/who-we-are/committees/ethnic-racial-issues> (last visited: 02/05/2025).



3.2. Policies

Influencing policies or reacting to the adoption of directly or indirectly discriminatory policies in healthcare is perhaps the most complex goal for bioethicists to achieve. Nonetheless, even in this case bioethics has several strings to its bow. First of all, many countries have established national bioethics committees with an advisory role to governments on health- and healthcare-related issues. These committees bring together experts from various disciplines and are usually set to have a certain level of independence from their governments or any other public health authorities. Typically, their role is limited to advising on the adoption of future policies or providing guidance in situations of legal uncertainty or legal vacuum, where new advancements or critical issues in medicine are at stake. The scientific authority of these committees could be leveraged if their role could be expanded, e.g., if they were conferred power enough to inhibit the validity of unfair policies or legal provisions that foster racism discrimination as it happened with the zero-tolerance policies to the detriment of migrants that I referred to above (section 2.2.). In this regard, I emphasized that many healthcare professionals, NGOs, and human rights advocates have strongly reacted to those inhuman and unfair rules which they felt as not grounded in the common morality. As a result, countless healthcare professionals have deliberately disregarded those provisions and defended everybody's right to access healthcare, regardless of their legal status. It is worth remembering that the ethical duty of care for the sick is at the foundation of modern medicine itself and still is a core element in the modern version of the Hippocrate's Oath. The professionals' disobedience contributed to opening the black box of those unfair policies, showing the material gaps, the conflicts, and the negotiations that separate *law in the books* from *law in action*. Therefore, that kind of disobedience can be also looked at as an example of *bioethics in action*¹¹¹, or else a peculiar way of *putting in force* bioethics, showing the strength of professional morality and thus paving the way to a form of activism in bioethics. Another example of this is the White Coats for Black Lives initiative, which was established in 2015 in the US as a medical students' movement. They aimed to fight racism and discrimination on three different levels. As they declared, "First, we must fight to eliminate racism in housing, criminal justice, education, and other areas as a threat to the lives and well-being of people of color. Second, we must end racial discrimination in the distribution and provision of medical care. Finally, we must demand that our medical schools create a physician workforce that reflects our nation's diversity and is prepared to fight for racial justice"¹¹².

3.3. Knowledge production

In the weeks following the death of George Floyd in May 2020, some of the most prestigious institutions of North American bioethics have adopted notable initiatives, aiming to dismantle latent prejudices and indirect racial discrimination within the community of bioethics. Among the latter, there is the "ABPD Statement on Violence, COVID, and Structural Racism in American Society" issued by the Association of

¹¹¹ C. BOTRUGNO, *Diritto alla salute e migrazioni internazionali: per una bioetica in azione*, in *Jura Gentium*, 16, 2, 2019, 102-126.

¹¹² D. CHARLES, K. HIMMELSTEIN, W. KEENAN, N. BARCELO, *White Coats for Black Lives National Working Group. White Coats for Black Lives: Medical Students Responding to Racism and Police Brutality*, in *Journal of Urban Health*, 92, 6, 2015, 1007-1010, 1008.

Bioethics Programs Directors¹¹³, which brings together affiliates and directors of Bioethics programs held in the United States and Canada. As emphasized by the APBD Statement, despite its commitment to promoting equitable access to healthcare, the bioethical community has failed in its attempt to address the *structural racism*¹¹⁴ that pervades contemporary societies. The Statement continues by recognizing that, although the idea of justice represents a *guiding principle* of the practice of bioethics, not enough has been done to counter the profound impact of racism in medicine, public health, clinical practice, and biomedical research. Even more clearly, the Statement admits that sufficient space has not been given to black, Indigenous, and other minority people, not only in assistance in the strict sense, but also within the academic debate, in universities, in specialized journals, in ethics committees, or in all those places where bioethics is practiced¹¹⁵.

In the same circumstance, The Hastings Center, through a post entitled “A Perilous Moment for Our Nation”¹¹⁶, has dedicated a reflection that lies at the intersection between pandemic emergency, poverty, and racism. The post contains a genuine self-criticism from the community of bioethicists, accompanied by a call to action to ensure that the inequalities that have manifested themselves dramatically in the juncture of the pandemic can be rebalanced in favor of the social groups most excluded from economic dynamics, social and cultural aspects of the industrialized West¹¹⁷,

As is known, the health emergency has brought the issue of the production and distribution of the anti-covid vaccine to the forefront of bioethics scholars. Also in this case, some prestigious institutions in the field of international bioethics have drawn attention to the need to work jointly so that all populations could have access to vaccination programs in an equitable manner and without delays, to avoid the most disadvantaged social groups and the poorest countries on the planet were excluded from this opportunity. In this context, the “Policy Briefing: Key Challenges for Ensuring Fair and Equitable Access to COVID-19 Vaccines and Treatments” published by the Nuffield Council of Bioethics¹¹⁸ has recalled some key factors that should be taken into consideration so that the objective of equal access to vaccination coverage could be achieved. These included the persistence of inequalities that limit access to universal healthcare, and the need to make a more equitable distribution of the burdens and benefits of vaccination trials between high- and low-income countries. In this context, a role of primary importance was conferred to the

¹¹³ ASSOCIATION OF BIOETHICS PROGRAM DIRECTORS, *ABPD statement on violence, COVID, and structural racism in American society*, 2020, <https://www.bioethicsdirectors.net/abpd-statement-on-violence-covid-and-structural-racism-in-american-society/> (last visited: 02/05/2025).

¹¹⁴ The notion of structural racism is often used interchangeably with other terms such as systemic racism, institutional racism, etc. For a critical reflection on the use of these concepts in empirical research, see T. H. BROWN, H. E. LEE, M. T. HICKEN, E. BONILLA-SILVA, P. HOMAN. *Conceptualizing and Measuring Systemic Racism*, in *Annual Review of Public Health*, 2025, 46, 1, 69-90.

¹¹⁵ *Ibid.*

¹¹⁶ M. SOLOMON, *A Perilous Moment for Our Nation*, in *The Hastings Center*, 2020, <https://www.thehastingscenter.org/news/a-perilous-moment-for-our-nation/> (last visited: 02/05/2025).

¹¹⁷ *Ibid.*

¹¹⁸ NUFFIELD COUNCIL OF BIOETHICS, *Policy briefing: Key challenges for ensuring fair and equitable access to COVID-19 vaccines and treatments*, 2020, <https://www.nuffieldbioethics.org/news/policy-briefing-key-challenges-for-ensuring-fair-and-equitable-access-to-covid-19vaccines-and-treatments> (last visited: 02/05/2025).

interface between public and private, since laws on industrial secrets and patents, as well as policies on the prices of medicines, can influence the testing of treatments and vaccines offered to the population¹¹⁹. The Center for Bioethics at Harvard Medical School also expressed solidarity with the black community and highlighted in a post titled “We Must Address the Racism Now”¹²⁰ how the combination of incidents of violence and the disproportionate number of black people who have died due to COVID-19 represent nothing more than the result of “centuries of profound discrimination and abuse” which have generated an unsustainable situation of ethnic and racial injustice. Also in this case, the awareness of the social roots of discrimination and racism is accompanied by the admission of not having done enough or in any case having failed in the fight against racism within academic institutions and in society. From this follows the related acknowledgment of the duty to immediately *activate* within the community of bioethicists to foment a process of change.

These statements, among others, certainly represent a turning point in the history of bioethics, given that they contain a clear admission of responsibility for the spread of racism in our society, not only within the healthcare system. Indeed, they acknowledge the existence of a tight connection between bioethics as a knowledge domain and racist violence as a phenomenon. It is worth remembering that the violence resulting from racial profiling has already been framed as a social determinant of health¹²¹, meaning that racist violence perpetrated outside the healthcare systems is already fully within the scope of bioethics. In this regard, it was indeed highlighted how confrontation with the police can trigger situations that may have highly negative repercussions for the health of those who are exposed to it, both on a physical and psychological level¹²². Beyond the possible lethal or sub-lethal consequences deriving from physical confrontation or the use of weapons, the impact of psychological stress deriving from the fear of being attacked must also be considered, both for oneself and for members of your social or family circle¹²³.

The centrality of knowledge as a proxy for dismantling racism and discrimination in healthcare is confirmed by a study¹²⁴ conducted a few years ago which assessed the composition of editorial boards of some of the leading scientific journals in the field of bioethics and medical ethics. The main result was a severe underrepresentation of scholars coming from low and medium Human Development Index (HDI). More in detail, the authors found that approximately 95% of the members of the concerned editorial board journals were based in high-HDI countries, less than 4% were from medium-HDI countries, and fewer than 1.5% were from low-HDI countries. At the time of the research, 8 out of the 14 concerned journals had no editorial board members from a medium- or low-HDI country, and 11 of them had no board members at all from low-HDI countries¹²⁵. In light of this, the authors emphasized that the editorial boards of these journals act as epistemic *gatekeepers* which would explain why bioethics “pays more

¹¹⁹ *Ibid.*

¹²⁰ CENTER FOR BIOETHICS HARVARD MEDICAL SCHOOL, *We Must Address Racism Now*, 2020, <https://bioethics.hms.harvard.edu/news/we-must-address-racism-now#:~:text=Today,%20and%20going%20forward,%20we%20at> (last visited: 02/05/2025).

¹²¹ C.T. LAURENCIN, M. WALKER, *Racial Profiling Is a Public Health and Health Disparities Issue*, in *Journal of Racial and Ethnic Health Disparities*, 7, 2020, 393-397.

¹²² *Ibid.*

¹²³ *Ibid.*

¹²⁴ S. CHATTOPADHYAY, C. MYSER, R. DE VRIES, *Bioethics and its gatekeepers: does institutional racism exist in leading bioethics journals?*, in *Journal of Bioethics Inquiry*, 10, 1, 2013, 7-9.

¹²⁵ *Ibid.*, 7.

attention to esoteric ethical problems facing wealthy nations than it does to issues such as poverty, hunger, and health inequities that are global in nature”¹²⁶.

Within the debates that revolve around epistemic racism, a major proxy of discussion concerns the *whiteness* of the knowledge used in healthcare and consequently also in bioethics¹²⁷. As also emerged by the above example of the journals’ board composition, whiteness here does not simply stand for *being white* with its counterpart of *being black* or *non-white*. Indeed, whiteness is not necessarily about skin color but first and foremost about the dominant cultural norms and ideologies that shape how knowledge relevant to both healthcare and bioethics is produced¹²⁸. From this perspective, whiteness could be understood as “a marker of location or position within a social, and here racial, hierarchy – to which privilege and power attach and from which they are wielded – and how this is complicated by a forgetting of the history of whiteness in the United States and by its current invisibility”¹²⁹. In light of this, whiteness should be considered as a hegemonic relation of power through which theories, practices, and principles are constructed, with the result of (re)producing white privileges and supremacy¹³⁰. Whiteness would be so rooted in both the practice of medicine and in bioethics that even its critic could be seen as an expression of its dominance or, as argued by Myser herself, a mere “inoculation of difference”¹³¹.

Scholars have reflected upon whiteness as a proxy for the formation of their (white) professional identity,¹³² particularly in relation to the (black) racialized *other*¹³³. Some of them emphasized the epistemic implications of the dominance of whiteness, which is described as an “absent presence” in the construction of their own identity: “My social location or, more precisely, my white identity influences what I see, the assumptions that focus my attention, the observations that I make, the problems I identify, the solutions that I generate and, more broadly, the knowledge that I produce”¹³⁴.

In a system of knowledge dominated by whiteness, black and other non-white people groups would be paradoxically subject to both “hypervisibility”, because their medical traits are turned into a “defining characteristic of their existence” or, the opposite, to “medical erasure”, where their needs remain “un-addressed and ignored”¹³⁵.

¹²⁶ *Ibid.*, 8.

¹²⁷ A. HO, *Racism and Bioethics: Are We Part of the Problem?*, in *American Journal of Bioethics*, 16, 4, 2016, 23-25; M. ROMANO, *White Privilege in a White Coat: How Racism Shaped my Medical Education*, in *Annals of Family Medicine*, 16, 3, 2018, 261-263; C. MYSER, *Differences from somewhere: the normativity of whiteness in bioethics in the United States*, in *American Journal of Bioethics*, 3, 2, 2003, 1-11; C. KONNOTH, *The Double Bind of Medicine for Racial Minorities*, in *Bill of Health*, 2020, <https://blog.petrieflom.law.harvard.edu/2020/10/13/double-bind-medicine-racial-minorities/> (last visited 01/05.2025); D. GUSTAFSON, *White on whiteness: becoming radicalized about race*, in *Nursing Inquiry*, 14, 2, 2007, 153-161.

¹²⁸ A. HO, *op. cit.*, 24.

¹²⁹ C. MYSER, *cit.*, 2.

¹³⁰ *Ibid.* In this regard, see also the recent analysis by C. N. Bell, E. A. Blackson, A. Anderson, K. Stojanovski, B. E. Weller. *Racism Counterfactuals in Health Research*, in *Journal of Racial and Ethnic Health Disparities*, 2025, 12, 4, 2071-2078.

¹³¹ *Ibid.*, 5.

¹³² M. ROMANO, *op. cit.*; D. GUSTAFSON, *op. cit.*

¹³³ D. GUSTAFSON, *op. cit.*

¹³⁴ *Ibid.*, 155.

¹³⁵ M. ROMANO, *op. cit.*

In parallel to the attempts to counterbalance the dominance of whiteness in bioethics, a critical rethinking of bioethics theories, categories, notions, and perspectives remains pivotal to combat racism and discrimination in healthcare. As seen before, over the last years an increased awareness about the value of race as a social construct has been reported. A clear example of this is the JAMA Guidance¹³⁶ which acknowledges that “race and ethnicity are social constructs as well as the important sensitivities and controversies related to use of these terms and associated nomenclature in medical and health research, education, and practice”. In such a context, they recommend that language and terminology of any content to be published in medical journals “be accurate, clear, and precise, and must reflect fairness, equity, and consistency in use and reporting of race and ethnicity”¹³⁷. The guidance also suggests not to consider race and ethnicity in isolation but integrating them by reporting “other sociodemographic factors and social determinants, including concerns about racism, disparities, and inequities, and the intersectionality of race and ethnicity with these other factors”¹³⁸. As discussed throughout this work, these recommendations can be framed into a vision that we have described as “constructionist” (section 2.3.), which is not free from contradictions and potential biases in the making of scientific evidence.

The recommendations adopted in the JAMA Guidance¹³⁹ can be seen as valuable insofar as they make evident the conventional value assumed by the notion of race and its derivatives when used as population descriptors in biomedical research. However, it must be considered that the debate around race as a social construct includes two conflicting orientations. Although they leave clear that race does not exist, to some¹⁴⁰ it is important to diversify samples used in biomedical research, particularly in the genomic one. As has been emphasized in this regard, “a fundamental limitation of precision medicine is the vast underrepresentation of non-European populations in the genomic samples needed for the development of genome-wide association studies. Not only does this worsen the performance of polygenic risk scoring for people of non-European (particularly African) ancestries, but also, by neglecting continents such as Africa—which harbors more genetic diversity than the rest of the world combined—this practice blinds scientists to a wealth of genetic signatures that could influence the identification of treatments for people of all races”¹⁴¹. Including research participants that better reflect the demographics of society would therefore avoid the risk of promoting an “exclusionary science”¹⁴².

In opposition to this view, other scholars stigmatize “racial inclusivity” as an emanation of medical racism¹⁴³. From this perspective, it has been emphasized that the effort to include racialized groups “risks re-enforcing the now-discredited belief that “race” is a biological category and allowing biological or genetic

¹³⁶ A. FLANAGIN et al., op. cit.

¹³⁷ *Ibid.*

¹³⁸ *Ibid.*

¹³⁹ *Ibid.*

¹⁴⁰ G. ADIGBLI 2020, cit.; A. BENTLEY, S. CALLIER, C. ROTIMI, *Evaluating the promise of inclusion of African ancestry populations in genomics*, in *NPJ Genomics Medicine* 5, 2020, 5; L. DUNCAN, et al., *Analysis of polygenic risk score usage and performance in diverse human populations*, in *Nature Community*, 10, 1, 2019, 3328.

¹⁴¹ G. ADIGBLI 2020, op. cit.

¹⁴² *Ibid.*

¹⁴³ P. KING, *Reflections on race and bioethics in the United States*, in *Health Matrix Cleveland*, 14, 1, 2004, 149-153; K. AZOULAY, *Reflections on race and the biologization of difference*, in *Patterns of Prejudice*, 4-5, 2006, 353-379; A. JABLONER, A. WALKER, *The Pitfalls of Genomic Data Diversity*, in *Hastings Center Reports*, 53, 5, 2023, 10-13.

differences to define racial and ethnic groups that are actually socially constructed”¹⁴⁴. Similarly, others have depicted the efforts of diversifying datasets in terms of a “predatory inclusion”¹⁴⁵, or else “a type of inclusion that works to the advantage of those who already hold power and not necessarily to the benefit of those who are being recruited”¹⁴⁶. Such a perspective evokes the idea of the “inoculation of difference”¹⁴⁷, i.e., a mechanism through which whiteness incorporates racialized factors to exert its control on them (section 2.3.).

An example of racial inclusivity came across the development of COVID-19 vaccines, where the recruitment of certain population groups labeled as *ethnic minorities* or *minor groups* was driven by the idea that these drugs should be efficacious along racial diversity¹⁴⁸. Without denying the need for seeking a broadly effective vaccine against COVID-19, such an effort to promote vaccine inclusivity has been stigmatized for being ripe with the biological notion of race¹⁴⁹, thus reinforcing disparities and harming people of color.

4. Conclusions

Fighting racism and discrimination in the healthcare field represents a crucial challenge for bioethics today. This challenge can be framed in what has been defined in terms of *everyday bioethics*¹⁵⁰, that is, something from which the integrity, the well-being, the guarantee of fundamental rights and therefore not just the health, but life itself of many today’s world depend. For this reason, the commitment of bioethics to combat racism and discrimination in the healthcare field must be considered an ethical imperative, and their pursuit of a goal of social justice.

As I have tried to demonstrate in this work, racism and discrimination in the healthcare field involve different levels and go well beyond their visible face, which is limited to the most striking manifestations and reported episodes. Furthermore, it has been shown that racist violence can be linked to the perpetration of racism and discrimination in the healthcare field. This is not only because racist violence causes suffering and death to the detriment of racialized groups. It is also because racism and discrimination in healthcare can have a direct influence on society by legitimizing and reinforcing practices and policies that directly or indirectly appear to be imbued with racism.

The notion of race maintains a privileged relation with biomedical research, particularly with genetics and genomics, a relation that turns phenotypical markers into a principle of social and epistemic construction of the world. Therefore, working on the epistemic level can be fundamental to show that racial categories are biologically unfounded and dismantle racial biases in the production of evidence. It is not a novelty

¹⁴⁴ P. KING, op. cit., 152.

¹⁴⁵ A. JABLONER, A. WALKER, op. cit.; K.-Y. Taylor, *Race for Profit: How Banks and the Real Estate Industry Undermined Black Homeownership*, Chapel Hill, NC, 2019.

¹⁴⁶ A. JABLONER, A. WALKER, op. cit.

¹⁴⁷ C. MYSER, op. cit.

¹⁴⁸ C. CAMPBELL, op. cit. *Racial Inclusivity in COVID-19 Vaccine Trials*, in *The Bill of Health*, <https://blog.petrief-lom.law.harvard.edu/2020/09/22/racial-inclusivity-covid19-vaccine-trials/#:~:text=By%20Colleen%20Campbell.%20Recent%20calls%20for> (last visited: 02/05/2025).

¹⁴⁹ *Ibid.*

¹⁵⁰ G. BERLINGUER, *Everyday Bioethics*, op. cit.; G. BERLINGUER, *Bioetica quotidiana*, op. cit.; BOTRUGNO, *Everyday Bioethics, Migrations, and Healthcare: Weighing the difference*, op. cit.



that bioethics can play a fundamental role here, by leveraging the entire range of knowledge and tools developed since its creation. But we must not underestimate the potential of bioethics also in fighting racism and discrimination in the everyday world, i.e., where bioethics is practiced, taught, and transmitted. This is the path toward a *bioethics in action*, i.e., more engaged bioethics, one that strengthens its relation with social justice and therefore strives for more just, inclusive, and equitable healthcare systems and societies.

Chapter