Ambivalence about Race

Expert Opinions on Using Racial and Ethnic Categories in Clinical Research in Sweden

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Abstract *This chapter examines the localized ambivalence surrounding the use of race in contemporary biomedicine: how race is constructed as both valid/relevant and invalid/irrelevant in a specific national setting. It is based on interviews with twenty-six expert professionals in Sweden who are directly or indirectly involved in clinical pharmaceutical research, including clinical researchers, research nurses, pharmacists, regulators, statisticians, and professionals from the pharmaceutical industry and clinical trial companies. The analysis explores how the professionals narrate their experiences and understandings of racialized concepts and categories. Most interviewees express strong postracial sentiments by rejecting race as a scientifically valid and useful concept. However, our analysis shows that race is nonetheless present in their professional experiences and discourses, enacted in three ways: through the mundane, everyday use of racial categories in clinical trials; through the conflation of ethnicity and race; and through a population genetics discourse about the scientific usefulness of race. We conclude that, despite moral, political, and scientific arguments against race, many informants express ideas about racial differences, and we discuss whether this may be explained by a high level of trust in medical knowledge production and the institutions regulating this knowledge production, including drug regulatory agencies.*

Introduction

The website of the Swedish Medical Products Agency (MPA) publishes questions from the public together with replies from the drug regulator. Under the headline "About ethnic Background in Product labels of Pharmaceuticals,"[1] a person who calls themself Vanessa asks why some drug labels mention patient skin color. As an example, Vanessa points to drugs for high blood pressure whose product labels refer to uses in "black patients" (svarta patienter). While the question does not reveal Vanessa's opinion on the matter, the

1 https://fragor.lakemedelsverket.se/org/lakemedelsverket/d/om-etnisk-bakgrund-i-lakemedelsproduktinformation, last accessed February 10, 2024.

MPA nevertheless replies: "We understand that choice of words such as 'black patients' may be perceived as inappropriate and denigrating," stressing that the agency "strives to describe patient groups in an equal manner, [and] where it is medically and scientifically acceptable" (our translation). After this caveat, the agency nevertheless goes on to explain that genetic differences between populations may influence uptake and breakdown of drugs in bodies and that this knowledge is important to pharmaceutical research. The agency also explains that the Swedish language product label is often a translation of the EU-wide English language label, in line with EU regulations on the matter, and that the use of concepts such as "black patients" may originate from foreign clinical studies that use other vocabulary or assign other meanings to concepts than what is customary in Sweden. As a final remark, the agency notes that vocabularies for describing ethnic background change over time and that some drug labels may include outdated concepts because the drugs have been on the market for many years.

The exchange between Vanessa and the Swedish MPA captures the key elements that make up the research problem addressed in this article, namely, the inherent ambivalence associated with the use of race as a concept and category in medical contexts in Sweden. On the one hand, the exchange illustrates how racialized concepts and categories such as "black" are used in Swedish medical contexts without definition or much further explanation. As the MPA explains, these concepts often originate from international clinical research categorizing patients by race and ethnicity (Mulinari et al. 2021), which then trickles down to Swedish—and, more broadly, European—clinical research (Mulinari and Bredström 2024b) and prescribing information (Mulinari and Bredström 2024a). On the other hand, the response by the MPA also reflects the official "post-racial" discourse (Goldberg 2009) in Sweden, which publicly chides notions of racial differences and translates race into the culturally more accepted concept of ethnicity. As in several other European countries, explicit talk of race in Sweden carries connotations of past racial biology and is therefore generally seen as negatively charged and pseudoscientific (Brännström 2018; Bartram et al. 2022). Thus, without knowing *why* Vanessa posed their question, the MPA feels the need to underline that the wording "black patients" may be experienced as "inappropriate and denigrating."

We aim here to delve into the ambivalence surrounding the concept of race in this specific context. Race is viewed as scientifically inappropriate and potentially demeaning, even as it is also perpetuated and normalized (Mulinari and Bredström 2024b). Our analysis is grounded in interviews with key stakeholders and experts engaged in pharmaceutical research and policy in Sweden. We engage their perspectives in dialogue with critical race studies that have explored the articulation of race in contemporary Sweden, and with social studies of science and medicine that have investigated the racialization of biomedicine in various national and disciplinary contexts. Through this investigation, our objective is to examine the localized circumstances under which race is constructed as *both* valid/relevant and invalid/irrelevant in contemporary biomedicine and to discuss its potential implications.

Methodology

Our research is centered on comprehending how race is conceived and constructed within contemporary biomedicine in Sweden. We adopt a poststructuralist understanding of race as socially constructed and perpetuated, including within medicine and biology, without being an a priori medical or biological "fact." However, the social constructions of race significantly influence individuals' lived experiences, including through healthcare. In Sweden, a growing body of literature has explored topics such as the presence of structural racism in healthcare institutions, affecting both healthcare professionals and patients (e.g., Hamed 2022; Wolgast et al. 2024). Critical race theorists highlight that contemporary constructions of race draw upon various notions of immutable differences, be they cultural, social, religious, or geographical, often substituting earlier ideas about biological distinctions between groups (Goldberg 2015). Nevertheless, some scholars have argued that the lingering role of medicine and biological research in shaping notions of race in the contemporary European context has received insufficient attention (Lentin 2020). This observation certainly holds true for the Swedish context, where many studies have concentrated on how static notions of culture have replaced ideas about inherent biological differences and hierarchies in racializing discourses (Schierup and Ålund 2011). Additionally, some critical race scholars advocate employing race (in Swedish: "ras") as an analytical tool and category for examining racism and prevailing discourses of whiteness and colorblindness in Sweden (e.g., Hübinette and Lundström 2014). However, there is limited research investigating the explicit and routine application of race as a biological concept in contemporary Sweden, as our study strives to do.

To explore the meaning-making around race in biomedicine in Sweden, we conducted qualitative semistructured interviews (Kvale and Brinkmann 2009) with twenty-six experts in the pharmaceutical scientific and regulatory fields representing different key actors. This included clinical researchers, research nurses, regulators, pharmacists, statisticians, and professionals from the pharmaceutical industry and clinical trial companies. The interview participants were strategically selected to represent different areas of expertise and experience. In addition, some snowball sampling led to additional participants, capturing the broader range of perspectives we were looking for. For example, while interviewing a key actor involved in pharmaceutical regulation at a national authority, we concluded that additional experience from within the same authority but covering other expertise areas (e.g., pharmacogenetics, product information) would add to the material we had already collected.

We specifically focused on clinical pharmaceutical research due to its relevance for discourses and practices around race and ethnicity in medicine (Kahn 2012; Mulinari et al. 2021). Clinical pharmaceutical research is often internationally collaborative, commercially driven, and subject to rigorous international and national regulatory standards. It is also a domain where experts in the field, as well as social scientists, patient activists, and regulators, have debated the use of race and ethnicity (Epstein 2007). Nevertheless, our previous research has shown that the application of race in Sweden extends beyond pharmaceuticals, encompassing various medical areas, such as dermatology and the measurement of lung and kidney function in physiology.

The interviews took place between July 2022 and December 2023, consisting of both individual and group interviews. Most interviews were conducted by both researchers. The project received ethical approval from the Swedish Ethical Review Authority (2021–02514), and we have deidentified names of the participants as well as workplaces, companies, and locations. Quotations have been translated from Swedish to English by the authors. We analyzed the transcribed interviews using principles of qualitative analysis (Silverman 2019). Specifically, we coded and thematized interview transcripts to capture the predominant ways in which participants narrated their experiences and understandings of racialized concepts and categories. Four main themes emerged. We will return to the themes after presenting the theoretical perspectives that guide our analysis.

Research Context

In addition to drawing inspiration from critical race theory, our research builds on science and technology studies, or STS, and medical sociological research that has scrutinized the "re-inscription of race" (Duster 2015) in contemporary biomedicine. Importantly, this renewed emphasis on racial differences in medicine has been driven to a large degree by the pursuit of more personalized, or at least more stratified, medicine in which a crucial step is imagined requiring studying human genetic variation within and between populations, with these populations categorized in terms of race, ethnicity, and nationality (Richardson and Stevens 2015). Critics have, however, questioned the use of race (along with ethnicity and nationality) as proxies for genetic variation, contending that human genetics research has contributed to the emergence of a new biological conception of race (Bliss 2012). This development has raised concerns for some scholars. Troy Duster (2015), for example, has described it as a "post-racial surprise," highlighting the irony of an increased interest in race in medicine coinciding with Western societies celebrating their own colorblindness and postracial ideology. But other scholars, such as Nikolas Rose (2007), have argued that the contemporary understanding of race in biomedicine should not be equated with earlier hierarchical notions of race. According to Rose, contemporary life sciences are less deterministic and more focused on the individual, enabling experts to better predict medical risks and optimize patient outcomes with biomedical technologies, including pharmaceuticals (see also Rabinow and Rose 2014). Moreover, some scholars have argued that race-based medicine can in fact enhance social justice, including health justice (Rotmi et al. 2013; Washington et al. 2022).

Promoting health justice is also the aim foregrounded by many who advocate for including specific racial and ethnic minorities in clinical trials, with policymakers and regulators in the United States leading the way (ibid. 2007). However, as shown by Steven Epstein (2007), in the United States this line of reasoning is readily upheld due to the "categorical alignment" between the social worlds of medicine, social movements, and bureaucratic administration, where racial categories, such as Black or White, are seen as similarly applicable across all realms. The categorical alignment is the result of a longer process of social movements seeking to improve the inclusion of ethnic and racial minorities (as well as women) in medical research in the United States (ibid.). However, a

major challenge arises when these US racial categories fail to align with population categories and conceptions used elsewhere in the world. For example, in the 1990s, international efforts to harmonize pharmaceutical regulation and industry processes raised disagreements over racial categories, as Japan's representatives from its drug regulatory agency argued that the unique homogeneity of the Japanese population required that drugs intended for authorization in Japan be tested on a Japanese population. In particular, they questioned the relevance of the three main racial categories proposed by the US representatives from the FDA (Caucasian, Black, and Asian), asserting that this did not correspond to the Japanese understanding of relevant population differences between Asian populations (Kuo 2008).

In our research, we ask what happens to the use of racialized concepts and categories when they are applied in the Swedish context, which lacks the same "categorical alignment." Not only do the US racial categories fail to align with the more emic categories used in Sweden (e.g., migrants, Swedes), but the concept of race as such is, as mentioned above, more or less taboo in public discourse (Brännström 2018). Since the 1970s, there have been repeated attempts to eliminate the term "race" from Swedish law, with several official inquiries addressing this issue. The key message of these investigations is that since race lacks scientific validity and carries undesirable historical connotations, it should not be used within Swedish law and public policy (SOU 2015). Proposed alternatives, such as "assumptions about race," or the replacement of race with ethnicity, would emphasize the socially constructed and "false" nature of race (ibid). Nonetheless, erasing the concept of race has proven legally complex[2], although recent legislation, such as the Discrimination Act from 2008, exclusively refers to ethnicity, not race (SFS 2008: 567).

Our study also ties into STS research on standardization as a way of naturalizing and normalizing concepts and objects (Timmermans and Epstein 2010). Standardization is fundamental for establishing reliable evidence across scientific fields, with, for example, international diagnostic and classification systems being as pivotal in biomedical research as they are in clinical practice. Numerous studies have analyzed the standardization of racial and ethnic categories in biomedicine, particularly in the United States. A key actor in this context is the U.S. Food and Drug Administration (FDA), which "strongly recommends" using standard US racial and ethnic classifications in clinical trials for drugs intended for the US market (FDA 2016). It is also of interest for our arguments below that while FDA points out that "the categories in this classification are socio-political constructs and should not be interpreted as scientific or anthropological in nature" (9), potential group differences in response to drugs are nevertheless seen as both "attributable to intrinsic factors (e.g., genetics, metabolism, elimination)" and "extrinsic factors (e.g., diet, environmental exposure, sociocultural issues)." Importantly, the distinction between intrinsic and extrinsic factors refers to a conceptual framework that distinguishes between race and ethnicity, with race being an example of an "intrinsic" factor, and more specifically a *genetic* factor, while ethnicity covers both "intrinsic" and

2 Legislators argued that there was a risk that a shift in meaning would make it difficult to accurately translate international declarations. It could also have unintended consequences, in particular making it more difficult to define and combat racist behavior (Prop. 2017/18:59).

"extrinsic" factors (ICH, 1998; 10; see Mulinari et al. 2021). That is to say, the FDA articulates race as, ontologically speaking, both socially constructed and biological in nature, and, epistemologically speaking, both scientifically problematic and therapeutically necessary (Kahn 2012).

Another key actor is pharmaceutical companies, which strive to enroll racially and ethnically diverse populations in clinical trials using US categories to adhere to FDA standards and enhance their social credentials. For instance, in 2021 Pfizer published a summary detailing the diversity of participants in its US clinical trials since 2011, with the intention of using it as a benchmark for the company's future efforts in diversity, equity, and inclusion (Rottas et al. 2021). Nonetheless, while pharmaceutical research primarily operates on an international scale, and regulators and global companies are key players spanning national boundaries, several studies reveal that local cultures and institutions continue to shape outcomes (Merz and Williams 2018; Merz 2021; Petryna 2009; Thiers et al. 2008). This is consistent with STS research showing how the application of research and regulatory standards aimed at ensuring consistency across different domains, including across countries, is influenced by local social and cultural factors (Timmermans and Epstein 2010). In the context of race and ethnicity, the lack of shared definitions of these terms between countries has been noted in several studies, which also problematize the various ways in which researchers attempt to deal with this definitional and conceptual ambiguity (Smart et al. 2008; Williams 2018). In our own research, for example, we have shown how the English word "race" is often replaced by the Swedish word for "ethnicity" (etnicitet) in Swedish language regulator–approved product labels that summarize the evidence from clinical trials (Mulinari and Bredström 2024a); however, at the same time, racial concepts and categories are routinely used in clinical trials conducted in Sweden (Mulinari and Bredström 2024b). In the following, we continue this line of inquiry by analyzing the discourse of key actors involved directly (e.g., researchers) or indirectly (e.g., regulators) in clinical pharmaceutical research in Sweden in relation to the use of racial concepts and categories.

Findings

"There is no such thing as race"

In our interviews, a prevalent sentiment echoed especially by scientists was the resounding rejection of the scientific value of the concept of race. One scientist with many years of pharmacological research experience emphatically stated: "There is no such thing as race." Furthermore, when confronted with pharmaceutical regulatory guidelines that referenced racial differences, he expressed strong disapproval, dismissing such notions as outdated. He contended, "It makes no sense," and firmly asserted: "Race does not exist. There are no human races."

Another distinguished scientist, a specialist in heart diseases, agreed with this point, declaring: "There is only one race, the human race." He nevertheless admitted to collecting information about the race and ethnicity of research participants, albeit only when mandated by a company's clinical trial protocol (see Mulinari and Bredström 2024b), and

very reluctantly. For him, using terms such as "black" was not only distasteful, but also deeply problematic from a methodological perspective.

> Z: The assessment [of race] is meaningless. It is often the patients themselves who assess [their race] or the staff. The patients assess according to the social context, not the genetic context. You are considered black if you live in a so-called black neighborhood where many black people live. [Regardless of] whether you are 100 percent black, both your mother and father are black, or 50 percent, or 10 percent.

He also returned several times to the idea that US categories are not relevant in a Swedish or European context:

> Z: "Are you from Hawaii?" Why would I be from Hawaii? Why don't you ask if I am from Gnosjö [municipality in Sweden] instead?
> Z: There is not a single African American in Sweden, by definition. And almost all of those [who are black] who are in Sweden are East Africans. And there is no [particular] genetic similarity between East Africans and West Africans.
> Z: Is a Spaniard in Spain white or Hispanic?

For this participant, racial and ethnic categories only made sense in their localized context. Thus, he suggested that US categories might be relevant in the United States, particularly for understanding social inequalities and their impact on health. However, beyond addressing social disparities in health, he considered these categories to be scientifically unsound concepts. He even saw a danger in their careless use, and he emphasized that "you are trying to construct a biological race which does not exist." Another participant, a senior manager at a private clinical research organization (which helps pharmaceutical companies with clinical trials) also voiced concerns about possible consequences. His main apprehensions were directed toward the future and the potential repercussions of generating race-based data:

> X: … All these things [information on patients' race] that we rely on in … pharmaceutical studies or [studies on] medical devices, or whatever we are looking at. There is an imminent risk that the data can be used in the wrong way. …
> Anna: What do you mean by using it in the wrong way? Would you like to elaborate on that? What is the risk?
> X: I'm convinced that what happened in Germany can happen again. We should not talk politics here and now, but I'm terrified of where we are heading. Considering that everything is digitized today too. The traceability is there where you can … Does it get into the hands of the wrong people at the wrong time … You don't know what this kind of information could be used for.

The scientific unsoundness of race, apprehensions about medical racism, and worries about the mishandling of racial data were but some of the concerns and negative emotions voiced by the individuals we interviewed. Several participants found it challenging to discuss the topic of race altogether. For instance, one participant explained her reluctance to use the Swedish word "ras" for race when translating English-language pre-

scribing information into Swedish, which is common practice in her line of work: "it's not used [in Sweden] and it feels very loaded, it feels like you would get complaints [if you use 'ras']." Another participant started discussing how she had "read something about hypertension and African Americans" but hesitated and commented, "it's hard to know what word to use." She feared that she might unintentionally express herself inappropriately when discussing racial differences. Others took a normative stance, emphasizing that in Sweden, phenotypic features like skin color should not matter. One participant stated, "As we see it in Sweden … It doesn't matter if you are red, yellow, or blue." Similarly, another participant asserted:

> K: I'm very much like … "No, I don't see the difference between people." If I would start looking at what they are just because [of skin color] … No, that's not me!

While it is important to note that not all participants held identical views, the discomfort experienced by all participants in one way or another underscores the salience of a "postracial" frame from within which they spoke, i.e. the widely held belief that race is deeply problematic scientifically and morally, and intimately tied to historical atrocities. However, notions of race still surfaced in the participants' narratives in various and sometimes contradictory ways. Below, we analyze three distinct modes of articulation of race.

A Standard Practice amid Silence

The first mode requires some sorting between what at first sight appear to be several embedded paradoxes; for example, how the use of racial categories is part of everyday routine in pharmaceutical clinical research yet unheard of by some professionals. Additionally, one of the initial surprises revealed in our interviews was that many of the participants had not given these issues much consideration before our discussions, despite their strong negative opinions about race and the value of racial categories, and even though some were aware of their routine use in clinical research. We might have expected that their impassioned responses during the interviews would have translated into robust debates and discussions with colleagues in their daily professional lives, but the narratives pointed in a different direction—towards silence and irrelevance of the subject matter. One participant with over two decades of experience of policy making in the pharmaceutical industry in Sweden, for instance, admitted that despite being aware that the recording of race and ethnicity was part of the protocol of many clinical trials conducted in Sweden, he had not devoted much thought to it.

This sentiment was echoed by several other professionals, such as staff involved in translating prescribing information into Swedish and individuals in pharmaceutical marketing roles. During a group interview, two participants responded with, "I had never thought about it to be honest," and, "Me neither," while another participant remarked that our discussion had "put ideas in their heads." For this last participant, the mere presence of racial categories in regulator-approved Swedish prescribing information was entirely novel information, and she was taken aback by the examples we provided (see Mulinari and Bredström 2024a).

This lack of awareness was not true for all participants, though, as several of them were indeed directly involved in categorizing patients by race and ethnicity in clinical trials. In these cases, ignorance was replaced by routinized but silent practice. All the participants with first-hand experience of applying racial and ethnic categories in clinical trials repeatedly pointed to the United States as the driving force behind the imposition of these categories in clinical research. One participant bluntly stated: "It's the United States that runs the show." These participants further described the role of the clinical trial protocol in which pharmaceutical companies instructed them to record the ethnicity of the patient as "Hispanic or non-Hispanic" and the race as "American Indian or Alaskan Native," "Asian," "Black or African American," "Native Hawaiian and other Pacific Islander," or "White." None of the clinical trial personnel we interviewed had experience with racial or ethnic categories tailored to a European or Swedish setting (see Bartram et al. 2023; see also Smith et al. 2022). Either the US categories were used, or race and ethnicity were not addressed at all.

A research nurse with extensive experience in completing the demographic information in what are called "case report forms" with clinical trial participants confirmed the challenges of this categorization. She described a scenario where a patient who was adopted from another country faces the dilemma of determining their appropriate category. In such cases, she actively collaborates with the patient and, if needed, resorts to online research to resolve the classification:

> Y: … Sometimes you end up in a discussion and [they] just say, "Well, I'm from that country and I'm adopted and from there, what will I be?" And then it can be like this; then you're standing there and have to google it in the end. … It can be a bit like this; you have to be a bit of a detective sometimes…
> Anna: And what do you do if someone says that "I have a black mother and a white father," for example?
> Y: Well, then I usually ask like this: "What do you identify as?" Then they can choose [for themselves].

However, in contrast to the United States, where diversity, equity, and inclusion issues are prominent concerns to stakeholders and experts, there appeared to be a conspicuous absence of discourse on these issues in the Swedish context. Notably, there are no Swedish guidelines for promoting racial or ethnic inclusivity in clinical trials, whether in private or public organizations, and we found no evidence of active recruitment based on race or ethnicity.

To sum up, the first mode in which notions of race were articulated in the interviews was as a routinized, everyday practice that neither provoked significant recognition nor concern. We interpret this mode as the outcome of a standardization process in clinical research in which the US categories are simply transposed onto other local contexts where explicit race talk is uncommon or even taboo due to postracial norms, leaving professionals to navigate silently through the resulting difficulties (Mulinari and Bredström 2024b).

Conflating Ethnicity and Race

The second mode of articulation was more familiar to everyone involved, including us as researchers, and it concerned the way race was replaced by ethnicity, sometimes alongside other markers of sociocultural difference (e.g., culture, nationality, religion, migration background or status), in resonance with a postracial discourse (Jonsson 2003; Lentin and Titley 2011; Lentin 2020; Bredström and Mulinari 2022). "We don't talk about race, but we do talk about ethnicity" was a recurring remark from the participants. In many cases, "ethnicity," in their vocabulary, referred simply to notions of cultural differences. In relation to pharmaceutical research, the participants mentioned, for instance, studies of medication compliance and cultural differences in attitudes towards medical treatments, or differences in diet and social habits among different ethnic groups that may affect the use and uptake of drugs.

While participants seemed more comfortable talking about cultural differences, it is worth noting again the absence of these more emic notions of "differentiating markers" in clinical studies and policy in Sweden. A research nurse involved in clinical trials confirmed, for instance, that in terms of social categories she had never come across a study that asked about country of birth or nationality, categories that are used in Swedish official statistics and epidemiological research.

However, what is particularly interesting to our research on race is that the interviewees sometimes simply translated ethnic categories into racial ones (see also Mulinari and Bredström 2024b), as in this case:

> D: We never talk about race in Sweden … we've never used that word, but we have perhaps said … talked about ethnicity, that you have a … that you are Caucasian, that's something that occurs quite often and that becomes relevant in this environment because we are Swedes and so on. (Policy maker, Pharmaceutical Company)

In his way of reasoning, therefore, the ethnonational term "Swede" could be subsumed under the racial term "Caucasian," which in turn is often used as a synonym for "white." Sometimes this implied shifting from ethnicity as a purely sociocultural phenomena to an implicit or even explicit understanding of ethnicity as something biological. Thus, in addition to the first mode, where race is enacted through the mundane and casual use of standardized racial categories in clinical trials, race is also articulated in relation to a postracial framework where ethnicity can become a proxy for race either by direct translation back and forth between ethnicity and race, or by a "biologization" of ethnicity.

Race through Genetics

Another participant, however, made a point of distinguishing between ethnicity as sociocultural and race as biological by referring to a key international pharmaceutical regulatory document (the "ICH-E5") that defines ethnicity and race as distinct concepts (ICH, 1998). This participant is involved in pharmaceutical regulation at a national authority. When explaining the relevance of studying potential racial and ethnic differences, the participant referred to the distinction—also made by the FDA (see above)—between in-

trinsic (e.g., genetics, metabolism) and extrinsic (e.g., environment, culture) "ethnic factors":

> B: Yes, there is, I can show this table [referring to a table in the regulatory document ICH-E5 adopted by both the European Medicines Agency and FDA on the role of intrinsic and extrinsic "ethnic factors"]. So, there's what's intrinsic and extrinsic. And what I work with … it's all intrinsic. So, it depends much more on the genes than on external factors. Yes, external factors can play a role. And that's where I make the difference between race and ethnicity [since the ICH-E5 table defines race as only intrinsic]. Because you can be, say, adopted from another country and then be of a different race. Whereas your ethnicity reflects where you live.
> Anna: So [race is] simply biological differences?
> B: Yes, biological.

As seen in the quote, when conceptualizing racial differences, the participant refers to "genes" and biological differences. Similar references to important genetic differences between populations popped up from time to time in the interviews, often presented as a scientific "fact." The main reference was to genetic differences in general, but there was also talk of differences in specific drug metabolizing enzymes, and the possibility of differential vitamin D production between groups due to differences in skin pigmentation, which in turn were genetically explained. Most participants mentioned that some people are slower or faster at metabolizing some drugs, which can have major health effects. While some participants emphasized that there are slow and fast metabolizers in all populations, many also pointed out that there is a greater frequency or likelihood of one or the other in different populations.

Importantly, as has been explored by many social science scholars, in such geneticized explanations, race often serves as a proxy for genetic differences (Bliss 2012; Duster 2015), and so it was in our case. Thus, there are several examples where ideas about genes were translated into the more racially coded notion of "blood":

> Z: Many of us have a lot of genetic influences [genetic heritage] that we have no idea about. I can have Asian or Southern European blood in me even if I don't know about it.

The third mode of articulation of race in the interviews was thus through ideas about population genetic differences. One of the scientists who vehemently opposed the idea that there is such a thing as race argued that there was still value in dividing the world into populations based on genetic similarity that were unmistakably similar to some traditional racial categories. Thus, he claimed that while Africans were too heterogeneous, "Asian" people were genetically homogeneous enough to be categorized as a group for the purpose of pharmaceutical research.

On the other hand, several participants pointed out that the US racial and ethnic classification would not accurately capture what they then saw as "real" genetic and enzymatic differences between populations. However, no one had a better suggestion on how to reliably label these differences:

> Z: If we agree on a global classification that is very rough. Then I could imagine that we would have ten classes or continents in general. It could be some kind of description and there might be some kind of genetic link. If my parents and I come from Europe or Africa or Asia … you could perhaps divide into three areas. So, it might be possible to find some kind of benefit from that.

Others were less careful and more or less conflated genetic variation with particular ethnic or racial groups, nations, or geographic regions. Some participants with extensive international experience referred, for instance, to race and ethnicity as proxy for what they saw as regional differences globally, differences that presumably would affect metabolism and thus should inform dosing instructions of some drugs. Another participant, who manages clinical trials at a pharmaceutical company, talked about how studies conducted in Africa make it easier to fulfil the FDA requirement of including a certain number of patients of a particular racial group. Black people in Africa, in this case, would presumably be accepted as genetically equivalent to African Americans, a position that many geneticists would ostensibly question. The point, however, is not to question the scientific validity of this claim, but to use it to exemplify how, in certain circumstances, genetic differences are articulated in ways that reinforce rather than challenge the existence of race.

Discussion

"If the aim is to have equal health, equal care and so on, then maybe you have to acknowledge or accept that there are different genetic predispositions," said one of the participants towards the end of our interview. Like most participants, she had talked about how race is an unscientific concept and how difficult it is to use given its historical baggage. However, after talking at length about discrimination in Sweden's health system, and the problem of unrepresentative clinical research data, she concluded by saying that while it is difficult to move beyond the negative connotations attached to race, knowledge about biological differences between groups must be pursued. *It all depends on what the knowledge of biological differences is used for*, she argues.

This participant is one of the few who comes close to the "inclusion-and-difference" paradigm that Epstein (2007) eloquently described as the existing biopolitical framework in the United States for understanding and dealing with social inequality through biomedicine. As Epstein shows, this paradigm suggests that being inclusive in medicine requires attention to immutable biological differences, including race, and he describes the processes through which clinical trial participants are recruited based on race and ethnicity, and how treatment recommendations are developed for specific racialized groups.

In the Swedish case, by contrast, strong discourses on racial or ethnic inclusivity and difference are absent, and so is the practice of recruitment based on race and ethnicity. Furthermore, the dissimilar categories used in broader Swedish society (Swedish, immigrant, Muslim, etc.) vs. pharmaceutical research (white, black, Asian, etc.) means that the categorical alignment that forms the basis of the paradigm in the United States is

missing. But this does not mean that race is absent in clinical contexts in Sweden. On the contrary, as we have seen in this paper, race is articulated and made relevant in various ways.

Our findings confirm that race continues to exist as an "absent presence" in Europe (M'Charek et al. 2014), and we also adhere to the critical race argument that race can be enacted through notions of ethnicity and culture in present-day Europe. In our research, however, we found evidence of ambivalent ideas about biological racial difference that we believe are not fully accounted for in the critical race analysis of postracial discourse. For instance, in the first mode in which race is present in the interviews, race is neither circumvented nor replaced by more culturally appropriate concepts such as ethnicity. Instead, it is applied in a rather blunt way, simply as race, in contexts such as clinical trials. We see this as an outcome of successful standardization in clinical research that silences existing tensions and leaves little room for alternatives. In a second mode, race is articulated via ethnicity to refer to supposedly immutable biological differences similar or identical to race. In a third mode, race is also "replaced," albeit not with ethnicity, but with genetics. In this mode, population genetic differences along perceived racial and ethnic lines are referred to as scientifically valid and relevant facts, which is paradoxical given the informants' strong rejection of the scientific value and usefulness of race.

By focusing on the ambivalence of race, where biological differences are simultaneously rejected and recognized, and where biological differences are put forward in a discursive national setting that otherwise focuses on culture, our study contributes to research highlighting how ambiguities are embedded and handled in scientific practices, including practices related to racial classifications (Panofsky and Bliss 2017; Will 2009; Vyas et al. 2020). Conceptualizing ambivalence and inconsistencies is a common thread in STS, and one important analytical point to be made is that the participants seemed to resolve the inconsistencies and contradictions of using concepts and categories that do not seem to fit—and indeed the paradox of using racial categories while resisting the notion that race exists—by attributing the use of racial categories to regulatory and corporate mandates beyond their control. Relatedly, several of the participants expressed great trust in the *institutions* of biomedical research in general and pharmaceutical regulation in particular. For example, some participants expressed confidence that if the FDA requires racial classification, it must somehow be based on solid scientific evidence, although they themselves could not point to that evidence. As one participant put it: "It's based on facts. And then the company just has to comply and include the information [on racial differences]." She also explained that if the study shows that a certain drug is metabolized differently by a certain group, then this information needs to be communicated to the healthcare provider and the patient. "It's about patient safety," she concluded. The fact that such trust in medical knowledge production and the institutions regulating this knowledge production triumphs over scientific, political, and moral objections urges us social scientists to continue investigating the biopolitics of medical research and to consider this research's pivotal role in the contemporary politics of race.

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