**We need more, not less, medicalisation. Discuss.**

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In this essay, I focus on the medicalisation of racism in the genomic era with rise of personalised medicine in 21st century United States of America(USA) through the case study of asthma. First, I establish that racism has not just undergone medicalisation but over-medicalisation. Next, I entertain the possibility that despite overmedicalisation, in fact

even more medicaliastion is needed, in order for personalised medicine to move past the stage of racialised medicine, to *unmask* race as a social category. Lastly, I cast doubt on this claim by situating medicaliastion as part of the same historio-societal forces that produced race.

Medicalisation refers to the processes by which social phenomena come to be perceived and treated as illnesses(Broom and Woodward 1996). Embedded within the definition of medicalisation is the ‘tendency [of] medical institutions to deal with non-conforming behaviour’(Broom and Woodward 1996: 358). The historical perspective is that medicalisation is the replacement of previous institutions of social control, including the church and the law, as behaviours gradually changed from sin, to crime, and eventually to sickness. Medicalisation is an example of social construction with the creation of the labels healthy and ill by medical professionals to make an ever increasing part of human existence relevant to medicine(Zola 1972). With medicalisation, there is tacit acceptance of the medical perspective as the dominant definition of a phenomenon(Conrad 1979: 511-512). Other authors have emphasised that medicalisation is not necessarily enacted by biomedicine, but by entities attempting to gain political benefit by recasting social problems as biomedical concerns to circumvent many of the inefficiencies of political processes, minimise and shift the burden of broad socio-political conflict around controversial issues(Sadler et al. 2009).

Race, in the USA, is defined as a socially constructed category that was created to justify slavery, genocide during European colonialism.(Omi and Winant 2011) Race manifests as Racism, which is a hierarchy of races, with European-Americans viewed as being inherently superior. Genomics is the study of the use of molecular information, such as DNA, to study molecular mechanisms of diseases and the impact of health interventions and influence of environmental factors on disease(Williams et al. 2020). The genomic era is the use of genomics to improve our understanding of the biology of health and disease and is marked by the complete sequencing of the human genome, in the international effort known as the Human Genome Project(Guttmacher and Collins 2003). Personalised medicine is the use of individual-level molecular differences to tailor individual-level interventions(Goetz and Schork 2018).

Social constructionism is the idea that the way humans understand the world, is through the meaning ascribed by other humans in the same society.(Harré 1986) In The Social Construction of What?, Ian Hacking provides a theory of the formation of social constructions, describing the seven engines of discovery including Medicine, Biology and Genetics(Hacking 2007). Hacking also names the entities involved through a five-aspect framework of interacting elements including classification, the people who have been classified, institutions, experts or professionals who generate or legitimate the knowledge and work within the institutions, and judge its validity, and use it in their practice(Hacking 2007).

In *Fatal Invention*, Dorothy Roberts, renowned legal scholar, investigates the ways biomedical science has reinforced race and racism, uniting research from both the social sciences with the biomedical sciences, relying upon published literature and interviews. Across chapters, she refers to her interview in 2008 with Dr Esteban Burchard, a respiratory medicine physician who is doubly trained as a genetic scientist at the University of California San Francisco. At time of publication in 2011, Dr Burchard was building a genetic database to collect ‘racially pure’ DNA, eschewing commercially available self-reported genetic databases(Roberts 2011: 192). He also established the Genetics of Asthma Laboratory whose goal is to identify distinctive molecular markers between ethnic groups to design targeted therapies for asthma in minority children(Roberts 2011: 302).

Dr Burchard’s work in looking for race-specific therapeutics is an illustration of the molecular re-inscription of race, in which genomic science is used to find differences between races when race as a biological category was disproven in 2003 with the completion of the Human Genome Project(Duster 2015). Asthma is a disease of the airways, which are hypersensitive to triggers such as dust or pollutants(GINA 2023) Dr Burchard’s research group purports to have found a mutation that was present in 24 African-Americans subjects, but not in the 96 Puerto Rican, 96 Mexican, 86 Caucasian and 7 Asian subjects with asthma, implying that the mutation is specific to populations of African origin. This mutation is involved in regulating the protein that affects the airways which he attributes this mutation as the cause of more severe asthma in African-Americans, and suggests this could be a novel drug target for African-Americans(Seibold et al. 2008). Utilising Hacking’s five-aspect framework of interacting elements(Hacking 2007) Dr Burchard’s work looks to classify people into races, and he occupies a position as an expert who generates and legitimises this knowledge through biology. As an academic at a renowned institution, and also as an advisor to Obama’s Personalised Medicine initiative(Burchard 2024) his work is squarely within institutions.

Simultaneously, upon further questioning by Roberts, Dr Burchard is made conscious of the way that race becomes biology, in which the lived experience of racism causes biological differences between races(Gravlee 2009). In explaining the mechanisms in which race becomes biology, Gravlee invokes Nancy Krieger’s, a renowned social epidemiologist, the ecosocial model. In this model, Krieger explains how disease is socially produced – for instance through socially inflicted trauma, resistance to racial oppression, economic and social deprivation, and social relations(Krieger,2001). In the context of asthma, asthma is socially produced as children who are ethnic minorities live in environments with greater risk of triggering asthma. One third of children living in public housing have asthma(Ely 2009) and this correlates with the higher rates of asthma amongst children of ethnic minorities. It is estimated 13% and 18% of African-American and Puerto Rican children have asthma, in contrast to only 8% of white children(Gold and Wright 2005). Dr Burchard believes that populations are biologically different(Roberts 2011: 305) and is aware of the interaction between social, environmental and genetic factors(Roberts 2011: 307) giving examples that physiological stress from racism can translate into hypertension and cardiovascular disease.

Through Dr Burchard, we see the medicalisation of racism through the twin phenomena of molecular reinscription of race and race becoming biology. Utilising Conrad’s litmus test, a social phenomena is medicalised if it can be defined in medical terms, described using medical language, understood through the adoption of a medical framework, or ‘treated’ with medical intervention(Conrad 2005). Race, which while is defined as a social construct, has become a biological construct, through the language of physiology and molecular data, under the framework of epigenetics. The management suggested by Dr Burchard is the development of a race-specific drug target.

But is this over-medicalisation? If medicalisation is defined as ‘when the institution of medicine oversteps its proper limits’(Parens 2013) Kaczmarek notes with the World Health Organisation definition of health as ‘a state of complete, physical, mental, and social well-being’, then there are no real limits to the institution of medicine as any or every aspect of individual and collective life can be seen as a health problem.(Kaczmarek 2019)

Kaczmarek provides guiding questions to differentiate between medicalisation and over-medicalisation, which I apply to racism below:

‘Does medicine provide the most adequate methods of understanding racism and its causes?’(Kaczmarek 2019)

Going by race as a social construct with implications on biology, and as per by Dr Burchard’s research, there still is much that needs to be elucidated in order to understand the mechanisms in which race causes molecular differences. In fact, Dr Burchard’s acquiescence that while his research shows differences in genetic expression, a large proportion of ethnic disparities in asthma can be attributed to social causes. Medicine does not deal with the causes of racism, only its implications. Hence, medicine does not provide the most adequate method of understanding racism and its causes, but only its upstream effects.

Does medicalising racism ensure the most effective and safest methods of solving it? (Kaczmarek 2019)

With medicalisation of a social problem, the solution is biomedical interventions. As per Dr Burchard, the treatment of inter-ethnic differences of asthma is pharmacological interventions that are for specific ethnicities which Dr Burchard has received a total of USD 51 million of National Institute of Health funding(Burchard 2024). With medicalisation of asthma, rather than the focus on the environmental triggers of asthma for the children living in public housing instead, resources are channelled into researching inter-racial pharmacological interventions that have not entered the market, and is unclear will start to yield benefit for ethnic minorities. It is unclear if the medicalisation of racism with pharmacological interventions is the most effective in solving racism.

Additionally, the molecular reinscription of race is not without its harms. Molecular reinscription lends credibility to race as a biological construct, and justifies racial profiling, in which race is used to make a judgement for a decision in important settings, such as in the clinical settings. Racial profiling has lead to significant harm to patients when medical decisions are based on race, rather than clinical presentation. Roberts discuss the case of Lela, whose diagnosis of cystic fibrosis was missed until she was eight years old when a radiologists who read her chest x-ray without seeing her physically, diagnosed her. Robert explains that the key reason was that she was African-American and doctors did not consider that she could be suffering from a disease predominantly affecting European-Americans(Roberts 2011: 275). While Dr Burchard attempts to acknowledge race, inadvertently he reinforces race as biology shows the deep entrenchment of race as a biological construct, and further entrenchments the logics that allow for racial profiling.

While there *is* over-medicalisation of racism, that the solution is *not less* medicalisation, but as Dr Burchard, *even more* medicalisation. While genomic medicine appears to be practising racialised medicine, as Dr Burchard expresses in a conversation with Roberts, this racialised state is but a step in moving towards personalised medicine.

I think where we are headed is that we will do genetic testing directly on Dorothy and be able to say, “Dorothy, regardless of your racial background, these are the drugs that should work for you.”

“What about in between that point and where we are now?” I asked.

“Right now, race is a proxy,” he emphasized. (Roberts 2011: 418)

Race as a proxy provides a large, identifiable group of consumers for drugs developed using genetic research. Medicine has changed significantly since medicalisation was initially described in the 1960s. With the rise of biotechnology, medicine and medicalisation is now more driven by commercial and market interests rather than by doctors(Conrad 2005). Roberts describes the paradox of personalised medicine – while genomic research allows for personalisation of medicines for patients, it simultaneously reduces the pool of patients as a market group for medications. Hence, in order to have an economically viable way of identifying patients who will benefit from genomic research and to guarantee profit from the production of medical treatment, race was used as a proxy(Roberts 2011: 447–448).

The main barrier to commercial implementation of personalised medicine is being overcome with reducing cost of gene sequencing technology. At the time of completion of the Human Genome Project in 2001, performing a whole genome sequencing(WGS), which is a technique used to identify all genomic material present in an individual, was USD$1 million; at time of publishing Fatal Invention, WGS costed USD$10,000 and now WGS costs less than a USD$1000(NHGRI 2024).

With this, the eventual realisation of personalised medicine as personalised medicine, rather than as racialised medicine, will be able to *unmask* race as a meaningful way of categorising individuals. Hacking describes unmasking as ‘challenging the extra-theoretical effectiveness of a doctrine’, to not leave a social construct intact(Hacking 1999: 56 - 57). More than merely exposing or refuting, which is to prove that a social construct is false – as did the Human Genome Project already disproven race to have biological meaning – personalised medicine will render race as a categorisation irrelevant, as Dr Burchard had explained to Roberts.

While Hacking has theorised mechanisms on how social constructions are formed and morphed with the *looping effect*, I build on his theory, on how social constructions are de-constructed, with the *unlooping effect*. The looping effect describes how the awareness of an individual’s categorisation, causes change in the individual’s behaviour and hence the categorised partake in their categorisation(Hacking 1999: 58). For example, race as a proxy, of how race becomes biology and the molecular reinscription of race are examples of the looping effect. Instead I posist personalised medicine theoretically could instead have the *un*–looping effect, when the categorised group, instead of morphing, dismantles the categorisation to begin with.

Or does it? The continuation of the conversation between Roberts and Dr Burchard suggests otherwise:

I call myself black or African American, but I’m a mixture,” I told him.

“You’re right, but you will always be treated as a black woman—just like Obama [will always be treated like a black man]. (Roberts, 2011, 418)

‘Biology is inherently historical, and its form of discourse is inherently narrative,’(Haraway 1992: 32) Donna Haraway writes in Primate Visions, a historico-ethnographic of the ways human notions of gender palimpsest on primatology, the scientific study of primates. ‘Those whose social definition of identity is rooted in the system of racism will not be able to see that the definition of human has not been neutral’(Haraway 1992: 37) Haraway explains that the historical superiority of particular structured standpoints for knowing the social world, extend to the scientific world. While Dr Burchard does not elaborate further on what exactly, or why Roberts will always be treated as a black woman, I interpret his quote in the context of the long histories that created race as a social construct. Medicine did not invent race, but simply adopted race from the wider societal context. Even if we possess the technology and availability to unmask race: it would be foolish to ignore the wider context that medicine operates in. Medicine is unlikely to unmask by its own for the same historical forces that produced race in the wider society, produced race in medicine too.

The question on medicalisation is not simply one of quantity, but one of how and who. Who is the *we* that needs medicalisation? While initially I had thought the we who needed personalised medicine were the ethnic minorities, to unmask race, by overcoming the economic barriers that prevent personalised medicine from fulfilling its possibility of being personalised. Yet, even the short history of personalised medicine has shown that despite the HGP disproving inter-racial differences in genetic data, and in fact intra-racial differences were greater than inter-racial differences with a 99.9% genetic similarity humans across races – race continues to be reinscripted molecularly. Taking a historical perspective, perhaps the we, is of who are the experts who generate and legitimise race to begin with.

*Bibliography*

Broom, D.H. and Woodward, R.V. (1996) ‘Medicalisation reconsidered: toward a collaborative approach to care’, *Sociology of Health & Illness*, 18(3), pp. 357–378. Available at: https://doi.org/10.1111/1467-9566.ep10934730.

Burchard, E. (2024) *(1) Esteban González Burchard, M.D., M.P.H. | LinkedIn*. Available at: https://www.linkedin.com/in/esteban-gonzalez-burchard/ (Accessed: 2 January 2024).

Conrad, P. (1979) ‘Types of medical social control’, *Sociology of Health & Illness*, 1(1), pp. 1–11. Available at: https://doi.org/10.1111/j.1467-9566.1979.tb00175.x.

Conrad, P. (2005) ‘The Shifting Engines of Medicalization’, *Journal of Health and Social Behavior*, 46(1), pp. 3–14. Available at: https://doi.org/10.1177/002214650504600102.

Duster, T. (2015) ‘A post-genomic surprise. The molecular reinscription of race in science, law and medicine’, *The British Journal of Sociology*, 66(1), pp. 1–27. Available at: https://doi.org/10.1111/1468-4446.12118.

Ely, E. (2009) ‘House Dust Yields Clue to Asthma: Roaches’, *The New York Times*, 6 April. Available at: https://www.nytimes.com/2009/04/07/health/07asth.html (Accessed: 2 January 2024).

GINA (2023) *2023 GINA Main Report*, *Global Initiative for Asthma - GINA*. Available at: https://ginasthma.org/2023-gina-main-report/ (Accessed: 2 January 2024).

Goetz, L.H. and Schork, N.J. (2018) ‘Personalized Medicine: Motivation, Challenges and Progress’, *Fertility and sterility*, 109(6), pp. 952–963. Available at: https://doi.org/10.1016/j.fertnstert.2018.05.006.

Gold, D.R. and Wright, R. (2005) ‘Population disparities in asthma’, *Annual review of public health*, 26(1), pp. 89–113. Available at: https://doi.org/10.1146/annurev.publhealth.26.021304.144528.

Gravlee, C.C. (2009) ‘How Race Becomes Biology: Embodiment of Social Inequality: Race Reconciled: How Biological Anthropologists View Human Variation’, *American journal of physical anthropology*, 139(1), pp. 47–57.

Guttmacher, A.E. and Collins, F.S. (2003) ‘Welcome to the Genomic Era’, *New England Journal of Medicine*, 349(10), pp. 996–998. Available at: https://doi.org/10.1056/NEJMe038132.

Hacking, I. (1999) *The Social Construction of What?* Harvard University Press. Available at: https://doi.org/10.2307/j.ctv1bzfp1z.

Hacking, I. (2007) ‘Kinds of People: Moving Targets: British Academy Lecture’, in P.J. Marshall (ed.) *Proceedings of the British Academy, Volume 151, 2006 Lectures*. British Academy, p. 0. Available at: https://doi.org/10.5871/bacad/9780197264249.003.0010.

Haraway, D.J. (1992) *Primate visions: gender, race, and nature in the world of modern science*. London: Verso.

Harré, R. (1986) *The social construction of emotions*. Oxford: Basil Blackwell.

Kaczmarek, E. (2019) ‘How to distinguish medicalization from over-medicalization?’, *Medicine, Health Care, and Philosophy*, 22(1), pp. 119–128. Available at: https://doi.org/10.1007/s11019-018-9850-1.

Krieger, N. (2001) ‘Theories for social epidemiology in the 21st century: an ecosocial perspective’, *International Journal of Epidemiology*, 30(4), pp. 668–677. Available at: https://doi.org/10.1093/ije/30.4.668.

NHGRI (2024) *The Cost of Sequencing a Human Genome*, *Genome.gov*. Available at: https://www.genome.gov/about-genomics/fact-sheets/Sequencing-Human-Genome-cost (Accessed: 2 January 2024).

Omi, M. and Winant, H. (2011) ‘Racial Formation in the United States: From the 1960s to the 1990s’, in *The Inequality Reader*. 2nd edn. Routledge, pp. 222–227. Available at: https://doi.org/10.4324/9780429494468-24.

Parens, E. (2013) ‘On Good and Bad Forms of Medicalization’, *Bioethics*, 27(1), pp. 28–35. Available at: https://doi.org/10.1111/j.1467-8519.2011.01885.x.

Roberts, D. (2011) *Fatal Invention : How Science, Politics, and Big Business Re-Create Race in the Twenty-First Century*.

Sadler, J.Z. *et al.* (2009) ‘Can medicalization be good? Situating medicalization within bioethics’, *Theoretical medicine and bioethics*, 30(6), pp. 411–425. Available at: https://doi.org/10.1007/s11017-009-9122-4.

Sahu, M. *et al.* (2022) ‘Chapter Three - Artificial intelligence and machine learning in precision medicine: A paradigm shift in big data analysis’, in D.B. Teplow (ed.) *Progress in Molecular Biology and Translational Science*. Academic Press (Precision Medicine), pp. 57–100. Available at: https://doi.org/10.1016/bs.pmbts.2022.03.002.

Seibold, M.A. *et al.* (2008) ‘An african-specific functional polymorphism in KCNMB1 shows sex-specific association with asthma severity’, *Human molecular genetics*, 17(17), pp. 2681–2690. Available at: https://doi.org/10.1093/hmg/ddn168.

Williams, G.A. *et al.* (2020) ‘Annex A: What is genomics? Definitions and applications’, in *Regulating the unknown: A guide to regulating genomics for health policy-makers [Internet]*. European Observatory on Health Systems and Policies. Available at: https://www.ncbi.nlm.nih.gov/books/NBK569502/ (Accessed: 1 January 2024).

Zola, I.K. (1972) ‘Medicine as an Institution of Social Control \*’, *The Sociological Review*, 20(4), pp. 487–504. Available at: https://doi.org/10.1111/j.1467-954X.1972.tb00220.x.