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Navigating conflicts of justice in the use of race and ethnicity in precision medicine

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Abstract

Given the sordid history of injustices linking genetics to race and ethnicity, considerations of justice are central to ensuring the responsible development of precision medicine programmes around the world. While considerations of justice may be in tension with other areas of concern, such as scientific value or privacy, there are also be tensions between different aspects of justice. This paper focuses on three particular aspects of justice relevant to this context: social justice, distributive justice and human rights. The implications of each for the use of race and ethnicity in precision medicine is described, along with how they intersect and potentially conflict with one another. By attending to these intersections, we aim to enrich and add nuance to debates over how best to proceed with precision medicine initiatives.

Key words: Justice; Precision Medicine; Distributive Justice; Social Justice; Human Rights

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1. Introduction

Precision medicine is often defined in terms of its *rightness*: ‘getting the *right* treatment to the *right* patient at the *right* time.’[[1]](#footnote-1) Here, ‘rightness’ is meant roughly in terms of ‘correct’ or ‘appropriate’ – what will be most effective at treating (or preventing, alleviating, etc.) a given condition. But talk of rightness also brings to mind other considerations, of morality and justice, that – while perhaps not intended in the definition – are nevertheless important, even crucial, to the development of precision medicine.

Of relevance is the sordid history of pseudo-scientific attempts to link race and ethnicity to genetics. While notions of natural racial and ethnic supremacy and inferiority certainly predate the emergence of evolutionary biology, genetics research has been leveraged from its very inception to pernicious ends. Herbert Spencer’s work in the 19th century was particularly influential in this regard, applying Darwin’s theories to argue that certain races and societies were, at a biological level, uncivilized and intellectually incapable.[[2]](#footnote-2) This gave rise to the 20th century eugenics movement, which pressed for the logical extension of social Darwinism – that members of certain undesirable groups should be selectively sterilized or otherwise prevented from reproducing, to improve the overall gene pool.[[3]](#footnote-3)

This is not to suggest that precision medicine today is at risk of revitalizing the coercive eugenics movement of the 20th century. Human rights discourse and our understanding of race, ethnicity and genetics have progressed substantially since that period. Nevertheless, concerns remain – particularly that the linking of race and ethnicity to genetics reinforces objectionable views about biology of race and ethnicity, which can in turn be seen by some as licensing disrespectful attitudes and discriminatory treatment. At the same time, there is a large push to expand precision medicine research to be of greater relevance to individuals currently underrepresented in international databases and studies that so far have centred on individuals of European ancestry. Race and ethnicity are sometimes used as proxies for under-represented groups, though differences in population history or environmental exposure may be of more direct relevance.

In this essay, we will attempt to make headway with some of these issues by exploring three aspects of justice in the context of precision medicine: social justice, distributive justice, and human rights. These are not the only aspects of justice potentially relevant to race, ethnicity and precision medicine (others might include proceduralism[[4]](#footnote-4) or political legitimacy[[5]](#footnote-5)), nor can we fully survey the entire applications of these three aspects in the context of precision medicine. However, the topics we do cover should give an indicative picture of the rich layers of justice-based concerns that have been or should be raised. Moreover, existing discussions tend to focus on just one aspect of justice or another.[[6]](#footnote-6) Exploring the three together allows us to highlight the tensions between them, and points towards potential avenues of resolution.

*Definitions*

Several concepts will need to be clarified before we proceed: precision medicine itself, as well as the three aspects of justice to be explored (social justice, distributive justice and human rights).

Precision medicine uses relevant biological, medical, behavioural and environmental information about a person to further personalize their healthcare. This could mean better prediction of someone’s disease risk and more effective diagnosis and treatment if they have a condition. While precision medicine technically relies on a wide array of information, genetic data has proven to be central to many initiatives and interventions pursued in its name. In part, this is due to the substantial role of genetics in causing disease and affecting the reaction to treatment. Genetics can also provide clues that could lead to the development of new treatments. The widespread use of genetics in precision medicine is facilitated by the availability of technologies that allow sequencing of the entire genome at a cost that is now affordable by many.

To develop clinically valid and useful innovations, researchers need access to a rich and voluminous amount of data collected by themselves or from other sources. Human tissue is in turn an important source of information, as genetic and other relevant data can be derived from it. This has prompted the proliferation of databanks and biobanks that seek to facilitate and promote precision medicine research by sharing information and samples.[[7]](#footnote-7) Justice in the creation and management of these databanks and biobanks will be one of the key focuses of this paper.

As for justice, we will not offer a single definition. Our purpose here is not to engage in political theorising. We are neutral on the theoretical relationship between the three aspects we identify – for example, whether they are all components of a unified central concept, or rather each has distinct normative groundings. Instead, we will focus on how these three aspects apply in the context of precision medicine, and the relationships between them. These were selected based on their prominence in the literature on precision medicine, and the interesting intersections between them which have relevant implications.

The first aspect of justice to be explored below is *social justice*. Social justice has an admirable history, represented by movements of suffrage, emancipation and civil rights that have propelled society forward – even if we are far from the realization of its ideals.[[8]](#footnote-8) For present purposes, we will understand social justice to consist in attaining (or coming closer to) equal dignity and respect for all within society. Dignity and respect in turn refer to a wide array of considerations, including but not limited to formal legal equality, non-discrimination, social standing and integration.[[9]](#footnote-9)

While social justice is concerned with dignity and respect, *distributive justice* is concerned with the fair distribution of goods among people. This may encompass material, transferrable goods (such as money or medicines), as well as aspects of people’s well-being (such as health and happiness), or ability to access those goods/attain levels of well-being.[[10]](#footnote-10) Here, we will focus on non-economic aspects of distributive goods, specifically, the distribution of the fruits of precision medicine research to ethnically and racially diverse populations that have, in different ways, contributed to their discovery and development.

Many violations of distributive or social justice would also seem to be in contravention of *human rights*. We can, after all, posit human rights to equal dignity, or a fair share of social resources. What sets human rights apart is less their substantive content (almost anything of value can be cast in terms of a human right), and more how they are framed and grounded. Human rights are things owed to us not in virtue of particular actions, abilities, relationships or group membership (including nationality), but purely based on the fact that we are human.[[11]](#footnote-11) Here, we will examine in particular one human right that has increasingly become part of the discourse on precision medicine: the right to benefit from the fruits of scientific research.

Each section below will further elaborate, within the scope of those aspects of justice, particular applications in the context of precision medicine, race and ethnicity.

1. Social justice

An abiding concern for decades is the fraught issue of the use of race and ethnicity in biomedical science.[[12]](#footnote-12) This has taken on newfound importance in the era of precision medicine, where the notion of ‘targeted therapies’ has raised the spectre of racialized medicine, and reliance on genetic data may slip into reification of race or ethnicity as biologically based.[[13]](#footnote-13) This debate is also reflected by the views of the authors of this piece, who have differing perspectives on the extent to which race/ethnicity should be relied upon in precision medicine research. Here, we summarise the nature of the concerns on each side, with a view to highlighting the problems of social justice that must be addressed, even if the solutions may not be agreed upon.

*The problems of using race & ethnicity in genomics research*

Genetically speaking, approximately 85% of all human genetic variation is found within any human population or group. The vast majority of human genetic variation does not distinguish between groups, even when the groups being compared are composed by self-identified race and ethnicity (both understood as social constructs used identify subgroups of individuals, with race often being associated with perceived shared features, and ethnicity associated with common culture, language and history).[[14]](#footnote-14) Nor is there great variation based on geographic origins, sometimes used as substitute for race and ethnicity.[[15]](#footnote-15) 7 to 15% of the human genetic markers vary between two groups from the same continent. Only 4 to 5% of genetic variation occurs primarily between groups from different continents. This between-continent variation represents a tiny fraction of our entire genomes (5% of 0.5%).[[16]](#footnote-16)

In short, there is no genetic variant that only exist in a particular racial or ethnic group. Thus, for example, cystic fibrosis is more commonly found in European populations, but the disease affects all racial groups in the United States.[[17]](#footnote-17) Similarly, until recently, citrin deficiency was thought to be found only in people of “East Asian” ancestry. In fact, it is pan-ethnic.[[18]](#footnote-18)

Genetic diversity between and among populations does exist. So scientists often talk about “clinal variation” when they talk about human genomic variations. Biologist Julian Huxley coined the term “clinal variation” to represent a geographical gradient in a particular trait across a species.[[19]](#footnote-19)

Nonetheless, there is a phenomenon of using ethnic and racial diversity as a proxy for human genetic diversity. Correspondingly, there is a growing body of work exploring how race and ethnicity continue to be used as a shorthand for genetic differences in the genomic era, and the issues of concern that these practices raise, particularly around our understanding of what race and ethnicity are, and how such uses do or do not address ongoing racial inequalities and persistent discrimination.[[20]](#footnote-20)

The use of race as a category in biomedical research projects is complicated.  Indeed, the American Sociological Association issued a statement on how and when it can and should be used, and by implication, when it should not.  For example, when trying to assess the way a society uses race to deliver health care, then race can and should be used.  There will be health consequences, some showing up as biologically different outcomes (higher rates of hypertension or a particular form of cancer, for example).  But to use race to differentiate among a population because of the assumption of biological or genetic differences is another matter. That is, if it is assumed by the research team that the differences between populations are bio-genetic in origins, as opposed to outcomes of different environmental exposures, then that constitutes a misguided and dangerous reification of race and ethnicity as a bio-genetic category.[[21]](#footnote-21)

*The advantages of using race & ethnicity in genomics research*

From a genetic perspective, if the human population mated at random, there would be no issue of subgrouping because the chance of any individual carrying a specific gene variant would be evenly distributed around the world. For a variety of reasons, however, including geography, sociology and culture, humans have not and do not currently mate randomly, either on a global level or within countries – and race and ethnicity do play a role in who people pick as partners.[[22]](#footnote-22) As a consequence, many variants (often the variants that are most useful for informing human biology) are substantially more common in certain subgroups. Failure to gather data on those variants by targeting subgroups (including by race/ethnicity) could increase healthcare disparities for conditions that have a genetic basis and are much more prevalent in an under-studied subgroup[[23]](#footnote-23) – an issue we return to in the discussion of distributive justice below. At the same time, access to data on these variants can also increase our ability to understand the biological basis of human disease.

It has been argued that a small number of genetic variants can effectively identify these sub-groups, which may be as precise, if not more precise, in defining the genetic background than by race/ethnicity.[[24]](#footnote-24) But two points are worth noting at this time.

Firstly, the time may come that some limited genetic information would be available for the entire population in the world, so that populations with unique population histories can be identified on genetic grounds rather than social constructs such as race and ethnicity. However, we currently lack such diversity in genetic datasets and tissue repositories, and it could be argued that race/ethnicity represent straightforward means by which we can ensure adequate representation of all sub-groups.[[25]](#footnote-25) It is entirely possible that other constructs, such as geographic diversity, could replace race and ethnicity as proxies of genetic diversity in this context.

Secondly, health also has many social determinants. In fact, it has been suggested that the social determinants of health have a greater impact than genetic determinants and may interact with the genetic determinants. Ethnicity may be associated with differences in environmental exposures.[[26]](#footnote-26) Ethnicity could be used as a proxy for these exposures, which have the potential to confound data analyses. As such, the inclusion of diverse ethnic groups may allow scientists to disentangle the effects of confounders which may be correlated in one population but not in others.

Still, sampling based on constructs other than ethnicity could achieve the same goal[[27]](#footnote-27) – so using ethnicity as a proxy is only useful insofar as datasets are not rich enough to capture potential environmental exposures that have an impact on health.

*Attempts at resolution*

Insofar as race or ethnicity are only relevant as proxies of actual causes of disease or health status, not causes themselves, the long-term solution to this conflict is to gather enough data from a sufficiently diverse global population. The actual causal mechanisms could then be used, and not problematic proxies of race or ethnicity. In the meantime, though, when the mechanisms have not been fully elucidated, a tension remains.

One attempt to address some of these vulnerabilities is to turn to the communities subject to racial and ethnic classification, to ascertain their views on the legitimacy of using such categories.[[28]](#footnote-28) As individuals and groups who would be primarily subject to the harms of racial classification, their perspective could help shed light on the extent to which those potential harms might be justified in particular cases. Community consultation models have other well-documented uses as well – for addressing not only concerns about race or ethnicity, but questions of privacy, the use of societal resources, the extent of benefits the community can expect, and so forth.

However, community consultation remains insufficient, not least because the issue of “molecular reinscription of race” remains.[[29]](#footnote-29) Indeed, the International HapMap Project,[[30]](#footnote-30) conducted community engagements, asking potential subjects what racial or ethnic descriptors they would like to be used. This contributed to the perception that the Project was, among other things, seeking to understand the biological basis of race – and thereby contributing to the biological reification of race.[[31]](#footnote-31)

These general social justice concerns about use of race and ethnicity, then, already pose a thorny problem for precision medicine programmes to tackle. In the next two sections, we will also highlight how these issues are complicated by intersections with two other aspects of justice, and offer some tentative suggestions on how they might be resolved.

1. Distributive justice

While precision medicine is understandably focused on whether clinically effective interventions (whether preventive or curative) can be developed, several aspects of distributive justice have also been raised. In particular, pressing concerns have been raised about which populations may be able to afford precision medicine innovations.[[32]](#footnote-32) However, as the focus of this paper is on the involvement of minority populations in precision medicine, we will instead examine the extent to which precision medicine innovations will in fact be applicable to a diverse range of individuals.

*Applicability*

The ‘targeting’ feature of precision medicine entails that any given intervention will primarily benefit one particular target group. For example, the finding that people with a certain genetic variant should not take a certain drug would benefit individuals with that profile. However, it would not particularly benefit those without the profile – and may actually burden them, if a genetic test to screen for the affected variant becomes routine prior to prescription of the drug.

This becomes particularly problematic from the perspective of distributive justice if precision medicine innovations are systematically more applicable (and thus beneficial) to some groups rather than others. And such appears to be the case. The data and tissue sources have predominantly come from Western countries, which results in findings of primarily relevance to those populations. As a result, international research has focused on genetic variants or environmental factors more frequent in those populations.[[33]](#footnote-33)

Resultant innovations are thus less applicable to those whose data and tissue are less well captured. For example, a recent Singaporean genomic study of thousands of individuals of Chinese, Malay and Indian descent found that over half of single nucleotide polymorphisms found in local genomes were completely absent from one of the world’s largest catalogue of genetic variants, dbSNP.[[34]](#footnote-34) This absence would inhibit the generation of insights related to those variants, which would be of particular relevance to the underserved populations that possess them in disproportionate numbers.

*Remedies of diversification*

If the over-reliance on data and tissue from Western countries is indeed considered a problem of justice (or, if not, a problem of science), an obvious solution is to diversify datasets and tissue banks. While considerable efforts are indeed underway in this regard,[[35]](#footnote-35) consideration must be given to potential tensions with social justice. An emphasis on diversifying genetic datasets on racial or ethnic lines can reinforce the mistaken notion that race or ethnicity are biological in nature. This is all the more problematic when race and ethnicity are inconsistently interpreted between the self-reports of different individuals and societies, further weakening genetic associations with those categories.[[36]](#footnote-36)

A firmer resolution to these tensions would be to focus diversification not on race or ethnic background, but other factors like geographic origin of the samples. There are substantial geographic clustering effects in terms of genetics, environmental factors and other variables of relevance in precision medicine.[[37]](#footnote-37) Geography does not come fraught with the same risk of biological reification that comes with the use of race/ethnicity – it is implausible that anyone would take such use to imply that geographic location is biological in nature.

1. The human right to benefit from science

The language of human rights is powerful. It invokes universal claims or obligations that bind us all, irrespective of our particular norms or cultures, and eschews any notion of contingency. Human rights also have a certain rhetorical force, especially when they are called ‘trumps’.[[38]](#footnote-38) This may not be strictly true – rights can and indeed must often be traded off against other considerations – but there is nevertheless the sense that, by classifying something as a right, it is given extra weight and seriousness.

*The right to benefit from science*

A number of considerations in precision medicine could be recast as human rights, including privacy concerns as well as the other two aspects of justice described here. But a particularly novel and important application has recently been raised: the right to benefit from science. This right has been argued to have implications for data sharing regimes in the development of precision medicine.

The right to benefit from science appeared in the 1948 progenitor of modern human rights discourse, the Universal Declaration of Human Rights. There, it was characterized in Article 27 as follows: “Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.”[[39]](#footnote-39) This was reiterated in Article 15 of the 1966 International Covenant on Economic, Social and Cultural Rights,[[40]](#footnote-40) a multilateral treaty that has legal force amongst all 169 parties.

We will not attempt to adjudicate the legal standing in international law, as our interest here is on ethics not legal matters. Indeed, the normative reasoning behind these declarations is worth taking seriously. A 1947 committee report for the Universal Declaration characterises the right to benefit from science as continuous with other positive rights like the right to education and health: everyone has a claim to a share in the provision of these goods, understanding that as societies advance people’s share will grow as the goods increase and multiply.[[41]](#footnote-41) But the right is not merely post-hoc, taking scientific advances as they are and ensuring the fruits are well distributed; it also encompasses people’s claim against their governments for such advances to be made in the first place. So, in the more recent 2009 UNESCO ‘Venice statement’ includes state obligations to “promote the development and diffusion of science and technology.”[[42]](#footnote-42)

*The right to sharing and informed refusal*

As already observed, diffusion (of data and tissue) is indeed crucial to the development of precision medicine. This, in conjunction with the right to benefit, has recently been taken by Bartha Knoppers and others (and adopted by the Global Alliance for Genomic Health)[[43]](#footnote-43) to imply “the right to access and share genomic and clinical data across the translation continuum, from basic research through practical, material application (e.g. diagnostics and therapeutics).”[[44]](#footnote-44) Emphasising this under-appreciated human right serves to provide a balance in situations where rights to privacy and ownership would militate against sharing.

Equally important, however, is the consideration of “the need to institutionalize informed refusal rather than leave it to already vulnerable individuals to question those in authority” articulated by Ruha Benjamin.[[45]](#footnote-45) In addition, we must carefully distinguish the idea of ‘the right to benefit from science’ and the right for scientifically relevant resources like data to be shared widely. The latter only follows from the former if such sharing will truly be of great societal value. With health and education, this may be obvious. With data as well as tissue, it is less so. Not only are the ex-ante prospects of public benefits (in terms of clinically actionable outputs) from any given project questionable, but the other two aspects of justice discussed here point to ways such sharing can exacerbate injustices.

We have seen how retention of problematic racial and ethnic classifications in the proliferation of data and tissue could exacerbate social injustices. So even if a given project handles the issue with sufficient care, avoiding any implications of a biological basis of race or ethnicity, it will be difficult to ensure that others who get hold of the relevant data or samples will be so conscientious. Well-meaning researchers can make objectionable inferences with such information.

In addition, we need to ask who is benefitting and whether those benefits are distributed justly. If benefits are centred on only a subgroup of society, then it would be misleading to claim that the human right to benefit from science is met by generous sharing regimes. The human right to benefit from science is only operational (that is, we can only confidently say that ‘everyone’ benefits from a sharing regime) when other aspects of justice are satisfied.

*Conditional sharing in precision medicine*

As a result, a liberal ‘open sharing’ approach championed by some[[46]](#footnote-46) may be incompatible with promoting justice. True open sharing means proliferation without condition or restriction. The sharer cannot have any control or guarantee what is done with the data, whether it will respect social justice or have benefits that are distributed fairly. And in light of the failings of current practices in these regards, we can expect that without such controls, injustices along the lines described here will continue.

Responsible sharing, then, requires conditions – not just with an eye towards maintaining confidentiality and respecting privacy or consent restrictions, but also with regards to the aspects of justice discussed here. Precision medicine programmes that aim to generate or maintain datasets or tissue repositories must therefore consider what sort of conditions might help realize these concerns of justice. For example, stripping out racial/ethnic identifiers would be one way to ensure non-proliferation of harmful associations, after due determination is made about the costs (if any) of such removals.

To identify an appropriate mechanism for ensuring these conditions are met, we could draw on the approach of the UK Biobank, which from its outset sought to ensure that tissue under its care was used for the public good.[[47]](#footnote-47) This means that any research request to access tissue and data must not only meet standards of scientific validity or data security, but also show how the use will promote health throughout society. However, the public good test remains mostly unspecified at present. Biobanks and databanks like the UK Biobank would therefore do well to explicitly include analysis of potential impact of sharing on racial or ethnic sensitivities.

In this way, it may be useful to adapt the model of ‘racial impact assessments’ proposed by Osagie K. Obasogie, analogous to more commonplace environmental impact assessments.[[48]](#footnote-48) Obasogie envisages these assessments as a regulatory mechanism pertaining to commercially available products like ancestry tests, but the same framework could be applied to primary research itself (at the IRB/REC level), as well as for sharing of data or samples (by a data access committee or a similar mechanism). Such an assessment would need to be mindful, among other things, of the ways that a given study might promote or inhibit different aspects of justice discussed here.

1. Conclusion

We have, in this paper, delved into three aspects of justice – social, distributive and rights-based – that are relevant to the use of race and ethnicity in the development of precision medicine. While individually they have received varying degrees of attention in the bioethical literature surrounding precision medicine, our contribution has been to consider them together, so the relationships and tensions between them can more clearly be brought to light.

Taking justice seriously in the development of precision medicine should not be seen as a barrier to valuable research. Distributive justice weighs in favour of continued efforts to diversify biobanks and genetic datasets to ensure the fruits of research can benefit a wide array of populations. At the same time, we should question the necessity of relying on racial and ethnic categories in such research, when other proxies for diversity such as geographic origin could suffice. These considerations are not limited to research projects alone, but also should be part of evaluation of access requests from biobanks and genetic databanks, including assessment where appropriate of including racial and ethnic tags.

As this paper reflects only a selection of issues of justice in precision medicine, it leaves open other topics and potential intersections within the scope of justice that may merit further investigation. For example, we set procedural justice considerations aside in this discussion, but an astute reader will notice some interesting connections. Social justice concerns extend beyond race and ethnicity to also include social economic exploitation, which could constitute an objection to commodifying data or tissue resources, even if the ultimate goal is to improve distribution of benefits. And we have not examined in great depth concerns redistributive schemes may have on individuals’ liberty and rights against coercive state interventions.

Nevertheless, we hope what we have been able to discuss in this space is not only of interest to ethicists grappling with difficult applications of moral theory to practice, but also practitioners in precision medicine who have the arduous task of shaping new and existing enterprises in both a scientifically robust and ethically responsible manner. In addition to the particular considerations examined here, it is worth emphasising that there can be no system that will satisfy all considerations of justice. At some level, trade-offs must occur, and a decision must be made about which considerations of justice must take precedence in a given context, and what compromises may be acceptable.

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