# Precision Medicine, Data, and the Anthropology of Social Status

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Published in *American Journal of Bioethics*
DOI: 10.1080/15265161.2020.1851813

One of the fundamental ethical ambiguities in giving over our information is that it allows the other party not just to help us better, but also to exploit us better. Today we are increasingly aware of this ambiguity wherever big data is used, and precision medicine is proving to be no exception. The gold standard of informed consent has long provided a way out of this ambiguity, but its justification has come under pressure as data reuse becomes more common. In response, some have pushed for more nimble consent models (Mckeown et al. 2021) and even for obligations to share data (Ballantyne and Schaefer 2018). However, I agree with Lee's call for an altogether different ethical framework, in terms of relationships and trust (Lee 2021). While Lee draws on the anthropology of gift-giving, the contribution here is an additional rationale based on the anthropology of status hierarchies.

## Status and Precision Medicine

Human communities, like those in many other species, are organized into status hierarchies, but unlike most other species where solely dominance (physical size, aggression, etc.) determines status, in the *Homo sapiens* also those who have a special competence and render an important service are accorded high status. In fact, the latter type of social status, or "prestige" (Henrich and Gil-White 2001) is so important that human communities have moral "service-for-prestige" norms (Price and Van Vugt 2014) aimed at preventing high-status individuals from exploiting their positions of privilege for anti-social or more purely egotistical ends. Conferring social status is thus a "gift" to the received in that it not only entails allows privilege but especially also obligations towards the community

This is highly relevant for the ethics of precision medicine, because from an anthropological perspective, research in precision medicine involves low-status groups (socioeconomically or socioculturally disadvantaged and/or ethnically stigmatized groups) giving their data to high-status groups (prestigious academics and academic institutions). On the one hand, this is necessary for the high-status group to better serve the low-status group: without this data, the resulting interventions are biased and only lead to further entrenching disparities, as amply discussed by Lee. However, on the other hand, this gift of data is also leads to an increased vulnerability of the low-status group: not only does the high-status group possess genetic information about the low-status group, but potentially also sociopolitical, economic, and environmental information.

Is it justified that this experience of vulnerability give rise to an attitude of distrust? It can be strange for scientists and their institutions to think of themselves as high-status agents that, despite their good intentions, may yet be distrusted by non-scientists – even though the ongoing pandemic has offered many vivid examples of such distrust (Desmond 2021). After all, scientific research is a common good, and scientific progress in principle (and usually also in practice) benefits all members of society.

## Grounds of Distrust

To the see how the grounds of distrust can form, it is instructive to look in slightly more detail at the lawsuit of the Havasupai tribal members against Arizona State University in the 1990s. Originally the Havasupai members had explicitly consented to ASU researchers using data from blood samples for diabetes research; however, subsequently the ASU researchers had used the same data for a different research project on schizophrenia. Not only that, but the ASU researchers had also transferred the personal data to yet other institutions to support research on migrations of populations (TallBear 2013, 144–45). There have been other similar cases: Tallbear reports a case in 2002 of data being initially obtained for research on debilitating rheumatoid arthritis – an urgent medical purpose – but subsequently reused for unrelated research projects and even transferred to others (TallBear 2013, 145).

From the perspective of the well-intentioned scientist, it is hard to see why the research subjects should not agree that the obvious benefits for the common good (scientific progress) justify data reuse – to the point of even obliging them to agree with the reuse(Ballantyne and Schaefer 2018). However, not only do they disagree, but they experience the data reuse as a betrayal of trust and even as a breach of rights.

Here the well-intentioned scientist misses the fact that the distrust is not about science, nor is it even necessarily about data. It seems to be about core values and having a voice. For instance, Tallbear reports distrust towards “Euro-American courts” which put the principles of individual autonomy and property rights at the center of their jurisprudence, and do not acknowledge concepts such as “spiritual harm” or the responsibility many tribe members feel to act as custodians towards their heritage (TallBear 2013, 181).

Why are such core values especially pertinent to research in precision medicine? When one gives consent to another party to use personal data, one can never be sure for which end it will be used in the future. Therefore, it is paramount that one trusts not only the *ends* to which the data will be put, but the *values* that guide the *decision-making process* of the other party. This trust is only possible when there is reasonable confidence that one’s own values are represented in that decision-making process. However, this is precisely what seems to be lacking, when even the arbiters of justice do not acknowledge the importance of spiritual harm or of protecting forms of heritage, ranging from rituals and ways of life to DNA.

This casts doubt on the wisdom of searching for more “nimble” consent standards that permit easier reuse, such as the “blanket consent” model, “meta consent”, or the “presumed consent” model (cf. Mckeown et al. 2021). Such looser consent models only are justified when there is significant trust already present. But trust is the more urgent issue, as also documented by qualitative studies on ethical judgments (Yardley et al. 2014; Desmond 2020), and when sufficient trust is absent, then asking for consent can appear to be a *demand* for consent. This *a fortiori* the case when low-status groups (again, in the sense of socioeconomically or socioculturally disadvantaged and/or ethnically stigmatized) are asked for their data. Their core values or concerns are not represented in societal decision-making, and they do not trust that they will be represented in the scientists’ future decisions on how to reuse the data.

## Demonstrating Trustworthiness

Precision medicine almost inevitably involves status differentials, and the ethical challenge here lies not in avoiding them, but in dealing with them appropriately. The first step is to acknowledge the existence of status differentials, and that these differentials erode the conditions for giving genuine consent. Thus, a researcher presenting an indigenous group with a presumed consent model may do so in the best of intentions to further the common good (scientific knowledge) and minimize future hassle of re-obtaining consent for new research projects. However, they may be unwittingly presenting them with a choice that can come across as coercive: "participate in this study (and give up your personal data), or you won't get proper healthcare". In general, having low status can mean having relatively little control over one's life course, a relative dearth of opportunities, and the experience of not being a full participant in society (Marmot 2004). This negative impact on self-esteem has been documented across cultures, genders, and ages (Anderson, Hildreth, and Howland 2015). Hence, when one has few alternatives, a simple request can quickly be perceived as a coercive demand.

The second step is a transition from "assuming trust" from others towards "demonstrating trustworthiness". Demonstrating trustworthiness is what it means to adhere to service-for-prestige norms when the other is not sure that these norms will in fact be followed. One concrete implication is that the researcher should communicate the intentions that the data will be used to ultimately serve (and not exploit) the giver of data. However, perhaps more importantly, it also means that the researcher (or research institution) listens to and tries to understand the concerns and values of the population under study. This can be a very difficult challenge when these concerns and values diverge strongly from the values of the liberal judicial system (autonomy, distributive justice, etc.). Achieving such understanding may also fall well outside the expertise of the researchers in question; nonetheless, it is needed to lay the foundation for a relationship of trust. Only when research subjects have confidence that researchers and research institutions understand their values or concerns can they justifiedly place trust in the researchers, since only then do they have reason to believe that future handling of personal data will be done with the appropriate respect.

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