Health Privacy, Racialization, and the Causal Potential of Legal Regulations

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Pyrrho and colleagues (2022) argue that the loss of health privacy can damage democratic values by increasing social polarization, removing individual choice, and limiting self-determination. As a remedy, the authors propose a data-regulation regime that prohibits companies from using such data for discriminatory purposes. Our commentary addresses three issues. First, we point out an additional problematic dimension of excessive health privacy loss, namely, the potential racialization of groups and individuals that it may likely contribute to. Second, we note that, in our view, the authors' argument for more regulation rests on an invidious comparison between the realistically described status quo and the idealized picture of the imagined regulatory regime that the authors briefly propose. Third, we argue that, despite existing regulations, both private and government actors frequently use private data in ways that lead to ethically problematic outcomes, *especially* when it comes to racialized communities.

Racial discrimination in the use of data is a widely discussed phenomenon. For instance, racial stereotypes are regularly perpetuated and reinforced by artificial intelligence (if only because of the biased input data), while racial inequality can be exacerbated by decision-making algorithms used, for example, to determine creditworthiness (Gillis and Spiess 2019). The loss of health privacy can contribute to the racialization of individuals and communities in a variety of ways.

First, medicine (understood broadly as health care and biomedical research) is itself a highly racialized field, for example,, due to institutional guidelines and recommendations to gather racial and ethnic data,

racial marketing in the pharmacological industry, or simply due to naive conceptualizations of racial categories. Consequently, the use of racialized health information can only reinforce the tendency to biologize racial health disparities, that is, to interpret them as biological, that is, genetic differences between members of different racialized groups, while their underlying causes are usually social and environmental factors. This is, for example, because it can strengthen the misleading impression that certain health issues are universal and essential "properties" of the representatives of some racialized groups (Malinowska 2021)—this is particularly troublesome in the context of the authors' worries about health-data privacy loss being connected with threats to a person's self-determination. Self-determination seems especially undermined (e.g., due to a reduced sense of subjectivity and agency) when one is treated merely as a representative of a certain group and thus dehumanized.

Moreover, broad access to people's health data can lead to an increase in social inequality when it comes to members of racialized communities. For example, health data may significantly affect someone's job prospects, access to credit, the cost of health insurance, and so on (Price and Cohen 2019; Gillis and Spiess 2019). As representatives of racialized groups statistically are at greater risk of developing health issues such as hypertension (resulting, for example, from worse access to health care, education, or adequate living conditions), the use of this information may further perpetuate or even deepen the already existing social disparities.

Although the loss of privacy when it comes to health data can contribute to strengthening racial

stereotypes and inequalities, we are aware that a complete lack of access to this data is not a solution to this problem. On the contrary, such data are necessary, inter alia, to analyze the health care system in terms of existing disparities (Zhang et al. 2017). It is therefore crucial to define precisely which actors can have access to health data, how it is to be used, and how to prevent or deal with potential data abuses.

Our second concern about the article is that the authors' argument for more regulation rests on a failure to compare like with like. Specifically, the authors adopt Shoshanna Zuboff's (2019) critique of data-hungry companies, claiming that their ever-growing appetite for as much user data as possible is an inevitable outcome of profit- and power-maximization strategies. Granting that this is indeed an accurate picture of "Big Tech's" motivations and incentives does not yet allow us to conclude, with the authors, that regulations are the way forward. This is because the authors do not present a credible, realistic alternative to the status quo. Instead, they rely on an idealized image of regulation and regulators as motivated by the pursuit of the common good and engaged in a virtuous feedback loop with the populations they supposedly serve.

There are reasons to doubt this idealization. For starters, government agencies may become subject to regulatory capture by industry interests, aligning their incentives with the incentives of the largest players in the data markets, and not those of an average data subject. Regulatory capture occurs when market actors find it more profitable to seek to directly influence regulators than to compete in the marketplace. The greater the regulator's power and scope, the greater is the incentive to capture it and tailor regulations and enforcement to suit the narrow aims of industry leaders. If market actors are indeed focused exclusively on maximizing profits and power (as Pyrrho and colleagues, following Zuboff, assert), then it is to be expected that they will devote substantial resources to effect regulatory capture. It is unclear to us how Pyrrho and colleagues hope to avoid this danger.

Second, regardless of the extent of actual regulatory capture, existing privacy regulations do seem to favor the incumbents, rewarding them with a growing market share and disproportionately lower compliance costs. For example, following the passage of the European Union's flagship privacy law, the GDPR, companies such as Google and Facebook increased their market share at the expense of smaller firms (Johnson et al. 2021). Thus, further regulations could well empower the very organizations that Pyrrho and colleagues take to be most culpable of misguided data practices.

Lastly, consider the structure of the argument for regulations that Pyrrho and colleagues offer: They describe the problematic uses of individuals' data as made by private companies, to then conclude that the companies should be prevented from using such data. But a parallel argument can be devised against leaving data governance to governments. After all, state agencies have themselves engaged in widely criticized data-based discrimination, from guiding law enforcement (using such tools as COMPAS, with a disproportionate impact on racialized minority communities; cf. Angwin et al. 2016; Malinowska and Żuradzki 2020), to deciding when to investigate a family for suspected child abuse (using algorithms that disproportionately target low-income families—cf. Eubanks 2018). Such examples give rise to worries about health-data governance at the hands of government agencies, just as the misdeeds of private corporations give rise to worries about giving *them* a relatively free rein when it comes to using and collecting health data. However, Pyrrho and colleagues do not give us reason to think that the former problems are more easily alleviated than the latter.

To be clear, we do not advocate a skepticism about all forms of regulation. Rather, we warn against a facile retreat into a Nirvana fallacy (a comparison of real-world systems with idealized alternatives) in the face of problematic treatments of data-subjects at the hands of private corporations. Granted, the way market actors deal with people's data is far from ideal. But we cannot conclude from this that a state-regulated data regime would approach the ideal more closely (cf. Chomanski 2021). Governments are data-hungry too, and we need care and caution in calling for their greater involvement in data governance.

Finally, we note that despite the intentions of both the regulators and, perhaps, the regulated institutions themselves, legal regulations in practice do not protect representatives of the most vulnerable social groups. A particularly clear example of this is the issue of circumventing the embargo on the use of racial data in the decision-making processes, for example, in banking. Despite antidiscrimination laws such as the Equal Credit Opportunity Act or Fair Housing Act (forbidding race, religion, etc. from being considered in setting credit terms or financing of real estate), in fact there is still considerable inequality in this regard. This is, among other things, because racialization affects many areas of human activity and translates into aspects such as economic status, level of

education, place of residence, and so on. It is enough, then, that decision-making algorithms are sensitive to data correlated with racialization to obtain results that are almost identical to those that consider people's racial identities (and that are just as discriminating) (Gillis and Spiess 2019). The already-mentioned COMPAS and child-abuse detection algorithms suffer from the same—or at the very least analogous—problem.

As representatives of racialized groups are statistically of worse health (e.g., due to the impact of racism), their health data may constitute an additional criterion that correlates with their racial identities and thus strengthen racial biases in decision making (even if the category of race itself is excluded from this process).

In sum, while the problems that Pyrrho and colleagues identify are pressing indeed, they neither exhaust the scope of questionable uses of health data, nor offer a persuasive solution to the issues raised. More caution is needed when crafting public policy proposals, especially when the fates of society's most vulnerable are at stake.

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