**Privacy, autonomy, and direct-to-consumer genetic testing: a response to Vayena**

**Abstract:**

In Vayena’s article ‘Direct-to-consumer genomics on the scales of autonomy’, she claims that there may be a strong autonomy-based argument for permitting DTC genomic services. In this response, I point out how the diminishment of one's genetic privacy can cause a relevant autonomy-related harm which must be balanced against the autonomy-related gains DTC services provide. By drawing on the conceptual connections between privacy and the Razian conception of autonomy, I show that DTC genetic testing may decrease the range of valuable options individuals possess, which impcats the extent to which would-be consumers can exercise their autonomy.

---

In Vayena’s article ‘Direct-to-consumer genomics on the scales of autonomy’, she claims that there may be a strong autonomy-based argument for permitting DTC genomic services.[[1]](#endnote-1) This point was made in the context of controversies surrounding a cease-and-desist order made by the FDA to 23andMe, a popular provider of DTC genomic services.[[2]](#endnote-2) The worries that many had (and perhaps still have today) revolved around whether DTC testing generated meaningful medical options which the average consumer could safely and reasonably engage with. While there is some contention about whether the information these tests provide is valuable and medically actionable, Vayena points out that there are “plural utilities” to providing these services. It would be myopic to focus solely on the medical actionability of these tests and how that bears on the value of these services. There are other ‘personal utilities’ to these services, such as indulging in one’s curiosity and obtaining valuable certainty about whether one is likely to develop a non-preventable, non-treatable disease. Following a Razian account of autonomy which focuses on the availability of valuable options, Vayena claims that DTC services can actually *promote* autonomy, understood in this sense.

My concern with Vayena’s argument is that it overlooks one respect in which DTC services can diminish or threaten one’s autonomy. “Autonomy” is confusingly defined in many ways so I want to be clear that my concern will be articulated using the same Razian conception of autonomy that Vayena deploys in her argument. To recap, for someone to be autonomous in the Razian sense is for them to be the “part-author” of their own lives, which requires them to have an adequate or valuable range of options through which they can decide how to live.[[3]](#endnote-3) According to Raz, a person is not autonomous if they have few choices available to them, only certain kinds of choices but not others, and choices that are either trivial or horrendous in their consequences. One more interesting observation Raz points out is that certain choices we make can c*lose* options that were previously open to us. A person might make a decision *now* that limits their own autonomy in the *future*. I want to suggest that this last point is critical to understanding an important autonomy-related harm of DTC testing: the diminishment of one’s privacy through the sale of one’s genetic information to large DTC companies.

My claim is that diminishments in one’s privacy can diminish one’s autonomy (in the Razian and other senses) because privacy and autonomy are intimately *interrelated*.[[4]](#endnote-4) To defend this claim, I will have to show three things. First, that DTC genetic testing diminishes one’s privacy. Second, that privacy and autonomy in the Razian sense are related. Third, that when one’s privacy is diminished, so is their autonomy and this may plausibly constitute an autonomy-related harm.

The first point is easy to make but it nevertheless depends on an understanding of what it takes for one’s privacy to be diminished. For example, imagine a person’s diary was left open on their desk and they had a neighbor who possessed high-powered binoculars and could see into the contents of their diary if they wanted to. For the sake of argument, let us stipulate that the neighbor never uses the telescope to read the person’s diary. Is their privacy diminished? While some theorists think that privacy is diminished only through the *access* of information about oneself, others seem to think the mere *accessibility* of one’s information can change their privacy status.[[5]](#endnote-5) If we think mere accessibility is sufficient, then we must claim that even though the neighbor will never read the person’s diary, the person’s privacy is diminished. However, intuitions about privacy diminishments are often very divided.

Regardless of how we might treat that scenario, what is it that happens when a person gives away their genetic information via a DTC test? When genetic information is given to companies like 23andMe, the agreements consumers enter make this information available to third parties for research and other business-related purposes.[[6]](#endnote-6) On either the accessibility or access condition, a person’s genetic privacy has been diminished because it is possible and highly probable this information will be or has been accessed by others. While consumers of DTC genetic testing likely sign an informed consent form, it is unlikely that they are aware of the ways in which this information has been accessed by others with negative consequences for them that they might not be aware of yet.

This leads me to the second and third points, which are that privacy and the Razian sense of autonomy are related such that diminishments in privacy cause corresponding diminishments in autonomy. Recall that the Razian conception of autonomy emphasizes having an adequate range of valuable options. If one innocently takes a DTC test now and perhaps finds out some unwelcome medical information, they may be obligated to report that information to insurance providers or employers. For fear of avoiding fraud, people will feel coerced to reveal this information, which could decrease the range of options people possess because they will be beset with worries about how to pay for medical treatments or obtain desired employment. If this results in them being unable to attend to other meaningful aspects of their lives, we might reasonably be concerned about the status of their autonomy. In this sense, one’s choice to take a DTC genetic test not only diminishes one’s privacy, it also impacts upon one’s personal autonomy as this ability is more difficult to exercise with potentially fewer valuable options. Therefore, DTC genetic testing can constitute an important autonomy-related harm.

In closing, I want to highlight how Vayena rightfully points out that for DTC genomics to enhance autonomy, it is important that these companies satisfy, among other things, adequate privacy protections. As such, she claims that the focus ought to be on how to regulate DTC genetic testing and not on autonomy, which as far she is concerned, can provide a *pro tanto* case for the legal permissibility of these services. I agree that precise regulatory processes are essential, but my argument about the privacy-influenced autonomy harms of DTC genetic testing may weaken this case somewhat. This is because it may close or impact one’s options long after a person takes these tests and in ways they might not be aware of. Of course, I am not claiming that this argument is decisive with respect to whether DTC genetic tests should be permitted. At best, I hope to have pointed out another kind of autonomy-related harm that must be weighed against the autonomy-related gains these services provide.

**References**

1. Vayena, E. Direct-to-consumer genetic testing on the scales of autonomy. *J Med Ethics,* 2015;41:310-314. [↑](#endnote-ref-1)
2. Holpuch, A. FDA orders genetic company 23andMe to cease marketing of screening service. The Guardian. 2013. https://www.theguardian.com/science/2013/nov/25/genetics-23andme-fda-marketing-pgs-screening. [↑](#endnote-ref-2)
3. Raz J. The morality of freedom. New York: Oxford University Press, 1986. [↑](#endnote-ref-3)
4. Véliz, C. Privacy is Power: Why and How You Should Take Back Control of Your Data. London: Bantam Press, 2020. [↑](#endnote-ref-4)
5. Skopek, J.M. Untangling Privacy: Losses Versus Violations. *Iowa Law Review*, 2020;105:2169-2232. [↑](#endnote-ref-5)
6. Brown, K.V. What DNA Testing Companies’ Terrifying Privacy Policies Actually Mean. Gizmodo. 2017. https://gizmodo.com/what-dna-testing-companies-terrifying-privacy-policies-1819158337 (accessed 5 November 2021). [↑](#endnote-ref-6)