Genomic Privacy, Identity, and Dignity

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Abstract

Significant advancements toward a future of big data genomic medicine, associated with large-scale public dataset repositories, intensify dilemmas of genomic privacy. To resolve dilemmas adequately, we need to understand the relative force of the competing considerations that make them up. Attitudes toward genomic privacy are complex and not well understood; understanding is further complicated by the vague claim of "genetic exceptionalism." In this paper we distinguish between consequentialist and non-consequentialist privacy interests: while the former are concerned with harms secondary to exposure, the latter represent the interest in a private sphere for its own sake, as an essential component of human dignity. Empirical studies of attitudes toward genomic privacy have almost never targeted specifically this important dignitary component of the privacy interest. In this paper we first articulate the question of a non-consequentialist genomic privacy interest, and then present results of an empirical study that probed people's attitudes toward that interest. This was done via comparison to other non-consequentialist privacy interests, which are more tangible and can be more easily assessed. Our results indicate that the non-consequentialist genomic privacy interest is rather weak. This insight can assist in adjudicating dilemmas involving genomic privacy.

As human beings, we attach great value to privacy; we therefore strive to control the access others have to us (Moore, 2010; Solove, 2008). This acquires special importance in healthcare, where people have a deep interest in restricting access to sensitive information about their health and protect the intimacy and integrity of their bodies (Allen, 2014; Beauchamp and Childress, 2013; Humber and Almeder, 2001). One central privacy concern in healthcare involves genetic, or genomic, privacy, which refers (*inter alia*) to the interest individuals have in keeping their genomic information personal (Gostin, 2017). The aim of this paper is to evaluate a central aspect of genomic privacy that has remained obscure. We do this by framing and articulating the relevant problem, and then reporting on a study we conducted that addressed it empirically.

1. The problem

Unprecedented advances in DNA sequencing technologies and in associated bioinformatics are beginning to have a transformative impact on medicine. Information obtained from whole genome sequencing is already having significant impact on cancer diagnosis and treatment, on the tailoring of pharmacological treatment (pharmacogenomics), and on understanding rare diseases (Manolio et al., 2019). The idea that personal genomic information, integrated with other clinical and environmental data, will enable precise individualization of healthcare underlies the grand vision of personalized medicine (Topol, 2019). The successful implementation of personalized medicine requires the establishment of large-scale genomic databases and the relevant biobanks (Hamburg and Collins, 2010; Hewitt, 2011), turning genomic medicine into a Big Data science. The more genomic medicine becomes an open data science, the more pressure there is to share genomic data freely and publicly, for promoting and translating genomic research (Vayena and Gasser, 2016). Hence, alongside the great promise they hold, these seismic developments in medicine naturally give rise to ethical worries regarding genomic privacy (Backes et al., 2018; Gutmann and Wagner, 2013; Shi and Wu, 2017; Ursin, 2008). The prospect of great advancement of healthcare as against the augmented risks to genomic privacy

thus engender a dilemma of medical ethics.

To respond to dilemmas optimally, we need to be able to judiciously assign relative weights to the different considerations that make them up. Only thus can we make responsible decisions on optimal tradeoffs between competing considerations. To assess the significance (i.e. the *importance*, not only the probability) of the risk of breach of genomic privacy, we need a good understanding of what the underlying interests—and, accordingly, the feared potential drawbacks—precisely are.

At this point, we should take a step back and briefly state what the right to informational privacy in general is meant and devised to protect. The moral reasons for this right can be divided, broadly speaking, into two categories: consequentialist versus non-consequentialist. While the first category involves protecting subjects from *harms* secondary to misuse of divulged personal information, the second involves protecting the private sphere from certain forms of scrutiny, which are deemed offensive *as such*, i.e. even without consequent harm to personal interests. This division applies in particular to genomic privacy. The consequentialist reasons for genetic or genomic privacy are well known. They include the potential for discrimination by employers or insurers, social embarrassment due to publicity of health problems, breakdown of family relationships by unintentionally demonstrating missing or unknown relatedness, anguish over proxy harm to family members, and more (Rothstein, 1997). These are the kind of considerations typically addressed in relevant discussions of privacy; they are not our business here. Non-consequentialist considerations, on the other hand, treat privacy as an intrinsic value, which refers, ultimately, to the protection of the sense of oneself as a separate person, and thus to human dignity (Bloustein, 1964; Ursin and Steinsbekk, 2012). Such considerations are notoriously more arcane and difficult to assess compared to considerations of harm. It is precisely this more esoteric component that this investigation will focus on, to help assess ethical dilemmas concerning (adequate protection of) genomic privacy.

Beyond the typical difficulties in exploring deontic concepts in general, and the elusive concept of human dignity in particular, in the case of dignitary considerations for genomic privacy we encounter yet a special hurdle, encapsulated

in the idea of genetic or genomic "exceptionalism." (Murray, 1997) The alleged "specialness" or "exceptional status" of genetic/genomic information has been attributed to various features: the unusual wealth of information it provides, its implications for family members, implications for future generations, its connection to stigma, racism, eugenics; and so on (Rothstein, 2005). However, beyond all these specific parameters, which can be assessed rationally, there remains, at the core, a more elusive element that transcends those, and which has contributed to the perception of a "DNA mystique." (Nelkin and Lindee, 1995) This "deeper" element arguably involves the intuition that DNA is fundamentally important to personal identity (Andrews, 1997). Consider the following illustrations: Walter Gilbert, the prominent Harvard biologist, opined that understanding human genetic structure is "the ultimate answer to the commandment 'Know thyself!'" (Miller III, 1998); the telling title of Carl Cranor's important anthology on genetics is *Are Genes Us?* (Cranor, 1994); Dorothy Nelkin and Susan Lindee call DNA "the ultimate identifier," (Nelkin and Lindee, 1995) and opine that DNA has taken on in our culture the role of "the Biblical soul." This last view is expressed explicitly in Nobel laureate Francis Crick's book *The Astonishing Hypothesis: The Scientific Search for the Soul* (Crick, 1994). Evelyn Keller sums up such perspectives in saying that "the gene was bestowed with the properties of materiality, agency, life, and mind" (Keller, 2000)!

The idea of the genome as the essence of humanity and of selfhood, alongside the ensuing idea that "genetic information is both potentially embarrassing and uniquely personal" (Annas, 1993) naturally entails an adamant requirement of genomic privacy, so as to protect "the most intimate and personal information that will ever exist" (Farkas, Goerl, and Hyer, 1997). It was precisely these ideas—that genetic information is "uniquely personal" and so deserves "unique privacy protection" (Annas, Glantz, and Roche, 1995)—which stood behind the (virtually unanimous) passing of the Genetic Information Nondiscrimination Act (2008) by the US Congress.

There has been much criticism of the idea that genetic information is "exceptional" and should be singled out for protection. Much of this criticism targeted the consequentialist reasons for genetic privacy, yet some argued more generally against a clear distinction between genetic and non-genetic information,

and, relatedly, against the idea that genetic information reflects our identities as humans and thus poses an exceptional threat to our privacy (Beckwith and Alper, 1998; Everett, 2004; Goodman, 2016; Green and Botkin, 2003; Murray, 1997; Rothstein, 2005). That debate has not been resolved. Lately "genomic contextualism" has been advocated as a middle ground (Garrison et al., 2019).

So, is genomic information specially connected to personal identity, and is it therefore deserving of special privacy protection on non-consequentialist grounds? Sketching the complexities raised by this question will allow us to zero in on the question we do find important to answer. The complexities involve three claims: (1) it is not true that genome equals personal identity; (2) even if it did: personal identity per se is not the parameter directly relevant to moral considerations of privacy; rather, the *sense of identity* is what counts; (3) not even every exposure involving elements of one's sense of identity correlates significantly with a sense of personal violation—which is what privacy requirements seek to avoid. Let us briefly review these points.

(1) Identification of one's genome with one's identity both clashes with commonsensical intuitions, such as that identical twins are not identical persons, and is untenable given our knowledge of the effects of epigenetic, environmental, and cultural factors on one's character and traits. It might be countered that the idea is not that genes are literally "us" but rather that the genome is *symbolically* expressive of who we are (Hellman, 2003). True or not, this more nuanced idea shows that personal identity is constructed via the hermeneutics of identity, which shifts the weight to the next parameter, focusing on the sense of identity. (2) Given the realization that personal identity is partly a function of a sense of identity (i.e. strictly third-person views on the "true" determinants of personal identity are wrongheaded), any imperative to protect personal identity must respond to people's sense of identity. And given that one's sense of identity doesn't fully overlap with a more objective, third-person perspective on personal identity, a person's privacy interests—on which we focus—correlate mostly with the former, not the latter. (3) Not even every element in one's first-person sense of identity is something one cares to protect from scrutiny. On the contrary: there are features of one's personal sense of identity that one seeks to expose. (For instance, a self-identified singer may be happy if clips

of her performances are watched by multitudes.) Hence the protection sought in privacy rights does not correlate well enough with exposure of elements of one's sense of personal identity as such; it rather correlates with those elements that are deemed intimate and whose exposure risks creating *a sense of personal violation*.

We can now return to evaluate the non-consequentialist element of genomic privacy—specifically, against the claim of genomic exceptionalism. We ask: *to what extent, if at all, is genomic information inherently intimate, and breaches of genomic privacy uniquely prone to generate a sense of personal violation?*

2. Empirical investigation

Let us recapitulate. The ethical issue of genomic privacy is acquiring greater urgency with the advancement toward big data, open access, genomic medicine. One ground of the right to privacy involves the deep interest not to be exposed, regardless of consequences, which in various ways connects to the fundamental value of human dignity. In the particular case of *genomic* privacy, this entails the interest not to have personal genomic information exposed, regardless of consequences. In order to evaluate dilemmas of genomic privacy adequately, we should be able to assess the weight of this specific interest. As explained, at the core of this interest lies the threat of experiencing a sense of personal violation due to sheer exposure of that which, we think, ought to remain intimate. Now the question of the extent to which people are prone to experience personal violation is not a question for armchair philosophy, but an empirical question of the psychological sense of personhood and dignity. Specifically, it has not been investigated whether or to what extent people associate sheer exposure of genomic information with a sense of personal violation. This is what we examine below.

We will present a survey that we conducted, which assesses respondents' sense of violation of privacy following different types of exposure. We conducted the survey in two waves, differing in the exact description of the genomic exposure scenario, as explained below.

2.1. Method

Participants. The minimal sample size to obtain a power of $1 - \beta = .95$ to find a medium effect size of 0.5 with confidence level $\alpha = 0.05$ for a paired comparison is 57 subjects. In each wave, we recruited one hundred respondents from the U.S., via Academic Prolific, to allow for screening based on an attention check (see below). One hundred and forty-five respondents passed the attention check in total (70 in the first wave, 75 in the second wave; 80 female, 63 male, and two who did not report their gender). Ages ranged from 18 to 75 (mean 31, median 28).

Procedure. After consenting to participate in the survey, respondents read a brief introduction informing them that they will read six different scenarios (Table 1) involving exposure, and be asked to indicate for each scenario to what extent (if at all) the exposure presents an unwelcome breach of privacy or intimacy. The instructions emphasized that (i) the exposure will not result in any harm, (ii) exposure is anonymous, and (iii) there is nothing inherently shameful about the exposed content. To ascertain that respondents focus only on the attitude toward exposure as such—i.e. on the non-consequentialist value in privacy—these clarifications were repeated before answering questions on each scenario. The instructions stated clearly: "opposition to exposure on grounds of privacy—if or to the extent that it exists in the scenarios below—would be based solely on *a sense of personal violation* elicited by *the sheer fact of exposure of that which, one feels, ought to remain intimate*." Furthermore, before proceeding to the scenarios themselves, respondents answered a comprehension question regarding the focus on the sheer sense of personal violation. Respondents who did not answer this question correctly could reread the instructions before returning to answer the question again.

Respondents read the six scenarios reproduced in Table 1 in random order, with each scenario presented on a separate screen. Each scenario referred to a distinct dimension of exposure, namely: body, genome, gestures, items, narrative, and thoughts. For each scenario, participants rated on a 7-point Likert scale (1 = "strongly agree"; 7 = "strongly disagree") their agreement with the

Table 1: Scenarios used in the study.

Category	Scenario
Body	A picture of **your naked body**, which was taken **for medical purposes** (there is nothing disfiguring about your body; it looks fine and well) was later **accidentally incorporated into a textbook on human health** for the wide public. You open the human health textbook and see **your de-identified (e.g. face completely blurred) naked picture**.
Genome	**Your DNA was taken for medical testing**. Now you learn that **the complete DNA sequence of your genome** was **accidently** added to a **biobank** (a database of human biological specimens). While it would appear **anonymously** (in the form, more or less, of a nameless nucleotide sequence, such as ATTAACGCGAT…[and a list of **specific traits potentially associated with it**]*), **it is available to be viewed** by stakeholders.
Gestures	In an **exhibition of exotic postcards**, you see on exhibit a **postcard that you wrote to a friend**, and which **accidentally** made it to the exhibition. Although the **names of sender and receiver are covered** to prevent possible identification, **you recognize that this is the greeting that you wrote** to your friend.
Items	**Your suitcase was x-rayed at the airport**, as all suitcases are. At another visit to the airport, you see **a public instructional video** that includes scans of suitcases. **You identify the scan of your own suitcase**, which **accidentally** made it to that video. All the items inside, such as clothes, toiletry, cosmetics, snacks, etc. **can clearly be seen and identified as such by the public** watching the video.
Narrative	A **psychotherapist** writes a diary that includes **true stories from the lives of his patients**, which came up in therapy. All names and some other personal details were changed, so that **no one can recognize** the true subjects of the stories—no one, that is, except the subjects themselves. **The diary is lost** and **accidentally** reaches a publisher, who publishes it as a book. You have been a patient of the therapist; you come across the book in a book store, and upon reading one of the stories, **you identify that it is your story**, as it came up in therapy, **told to the public** between these pages.
Thoughts	Assume that functional brain imaging techniques (such as functional MRI) have been perfected to the point where they are able to **identify particular thoughts** by **scanning the brain** (e.g. a thought such as "I should meet Henry at the gym after work"). You underwent such functional brain imaging. **The results accidentally made it to a non-confidential file**. Now, in some public demonstration of the sophisticated achievements of brain scanners, **you identify your thoughts being exposed to the crowd**.

*Note: The bracketed phrase in the Genome scenario appeared only in wave 2.

following statements:

1. This experience would involve a sense of personal violation.
2. This exposure is a breach of personal privacy.
3. This exposure offends against what is and ought to remain intimate.
4. This experience would make me feel uncomfortable.

Due to an inherent ambivalence in the concept of "genomic information" (on which we elaborate in the discussion below), we conducted the study in two waves. In the first wave, the Genome scenario described genomic information as referring to a mere "nucleotide sequence," while in the second wave it also encompassed "a list of specific traits potentially associated with it" (as shown in the bracketed section in Table **??**).

As an attention check, we next asked respondents to mark the topics that appeared in the scenarios out of a list of nine topics, presented in random order. The three distractors were family history, SAT scores, and credit history. We excluded from the analysis respondents who did not mark all six scenarios (and no other) correctly. The survey concluded with general demographic questions. (See the Appendix for the complete protocol.)

2.2. Results

Cronbach's α for the four questions is .945. To compare the different scenarios, we therefore calculated the average rating for each respondent and scenario across the four questions. There were no meaningful or significant differences between the two waves. The absolute differences in the means ranged from 0.04 (Thoughts) to 0.287 (Body) on the scale of 1 to 7. Mann-Whitney tests yielded p-values ranging from .110 to .664. Importantly, the mean sense of personal violation associated with exposure of genomic data (Genome) was *lower* in the second wave, indicating that adding the phenotypic interpretation of the exposed genomic data did not increase the perception of breach of privacy. We therefore report the aggregate results of the two studies.

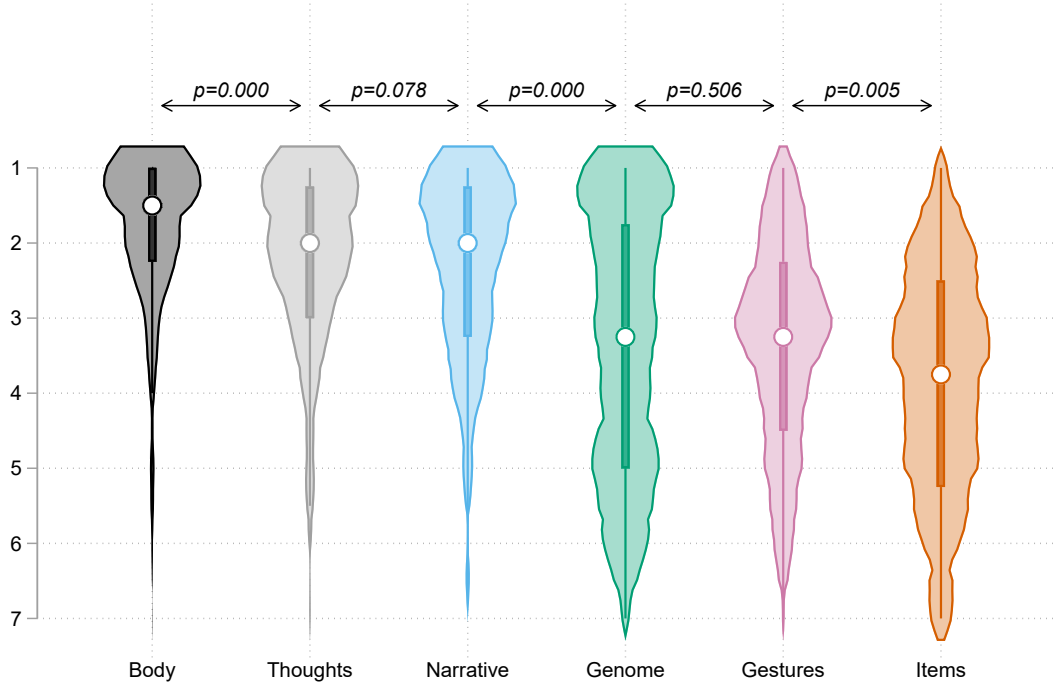

Figure 1: violin plots of responses. The plot presents medians, interquartile range and kernel density plots. Responses ranged from 1 (high breach of privacy) to 7 (low breach of privacy). Reported p-values based on Wilcoxon matched-pairs signed-ranks test.

Figure 1 presents the distributions of the responses for each scenario. The plot shows that the highest perceived breach of privacy is associated with Body (median $=$ 1.5, where 1 is the highest breach of privacy). Next are Thoughts and Narrative (median $=$ 2); Genome and Gestures (median $=$ 3.25); and finally, the lowest perceived breach of privacy is associated with Items (median $=$ 3.75). The perceived breach of privacy is significantly lower for Genome than for Body, Thoughts and Narrative ($p < .001$ for all pairwise comparisons, two-sided Wilcoxon matched-pairs signed-ranks test). It is virtually the same as for Gestures ($p = .506$), and is significantly higher than for Items ($p = .006$). These results are qualitatively replicated if we include all 200 respondents or conduct a parametric repeated-measures ANOVA.

3. Discussion

In their authoritative review of the literature on attitudes toward genetic privacy, Clayton and colleagues conclude that the emerging picture is "complex and riddled with gaps," and that "it is important for future studies to conduct investigations at greater depth into which concerns about genetic privacy are most salient to people" (Clayton et al., 2018). In this paper we concentrated on the non-consequentialist component of genomic privacy, which has thus far virtually escaped specific investigation. This neglect constitutes a lacuna in our ability to assess ethical dilemmas involving genomic privacy.

What does the non-consequentialist idea of genomic privacy as such refer to precisely? Here we confront an inherent ambivalence, which led us to check separately two formulations of Genome (hence the two waves of the study). On the one hand, "genomic privacy" can refer to the nucleotide sequence and to the list of specific traits potentially associated with it. This wide interpretation is reasonable to the extent that we think of the genome as a form of "machine language," whose essential significance (just as in computer code) derives entirely from the higher phenomena it encodes. If the very essence of the genome is in being a proto-language whose meaning is in its translation, then that translation belongs to its essence—it is not a discrete consequence. Relatedly, in the specific context of our study, an argument for the wide interpretation is that it allows better alignment of Genome with the other categories, since the nucleotide sequence as such is incomprehensible to us and thus meaningless, whereas the other categories are much more meaningful to the average person. On the other hand, the narrow interpretation of "genomic privacy" as referring to the mere nucleotide sequence is reasonable too. The list of traits encoded by the genome makes up the *phenotype*. Hence, the wide interpretation mandates viewing all *genomic* privacy as including phenotypic privacy of sorts. But this seems like a change of focus compared to the interest in genomic privacy per se. To emphasize: there is no one-to-one function between gene and phenotype (which would have made referring to the genome by its phenotypic translation more palatable), and phenotypic expression is heavily influenced by environmental factors. Hence, we cannot view the phenotype as a straightforward

translation of the genes; this drives a large wedge between genomic privacy, which is our focus, and phenotypic privacy, and it militates against the wide interpretation. Space does not allow adding considerations in support of each of the two interpretations—the bottom line is that they are both viable, and so we checked both. Interestingly, we found no significant difference between attitudes toward privacy as a function of interpretation; we could therefore sum results from the two waves.

Our question about a non-consequentialist "sense of personal violation" (or a sense of "breach of personal privacy," etc.) in response to the mere exposure of personal genomic information yielded a median answer of 3.25, i.e. only weak agreement. This is by no means an obvious or trivial result, and the insight it provides should help evaluate ethical dilemmas regarding genomic privacy. That being granted, assigning a number or even a short descriptive term to the depth of one's interest offers limited understanding. Hence, we opted to clarify the strength of the non-consequentialist interest in genomic privacy by comparisons to parallel dimensions of life, the strength of whose claim to privacy we can more intuitively assess.

Do these comparisons provide empirical support for an "exceptional" interest in genomic privacy? The answer seems quite clearly negative. Historically, the naked body has been the paradigm of what is and ought to remain intimate. In our results, the category "Body" elicited the strongest interest in privacy, confirming the paradigmatic status of nakedness (in unwanted circumstances) as elicitor of an acute sense of personal violation. Similarly, familiar dimensions of the inner life: our personal stories (Narrative) or our personal thoughts, even when their content is not especially intimate, are experienced as a private realm, whose uninvited exposure elicits a significantly stronger sense of personal violation than exposure of personal genomic information.

The intensity of aversion toward sheer exposure of personal genomic information came out in our study as almost identical to that toward exposure of a greeting one wrote to a friend. (Recall that according to our instructions there shouldn't be anything especially embarrassing about the content of the greeting.) Without attempting to articulate precisely the intensity of the sense of personal violation associated with such exposure, we can safely say that it

seems relatively mundane, and does not warrant an account in terms of an "exceptional" demand for privacy, reserved to that which is strongly associated with the essence of personal identity.

Another instructive comparison is between Genome and Items. While our results suggest that Items are perceived as less private than Genome, that difference, though significant, is very small (half a point on the 7-point scale, or 0.26 standard deviations—i.e., Cohen's d effect size; the difference between Genome and Body is almost three times larger: $d = 0.73$). This suggests that the sense of violation of privacy associated with sheer exposure of personal genomic information is, apparently, not much higher than the comparable sense of violation experienced when mundane contents of one's bag ("such as clothes, toiletry, cosmetics, snacks, etc.") are exposed. While such exposure might be experienced as somewhat unpleasant, it is hard to describe this experience—the like of which is so prevalent in airport security checks these days—as constituting an exceptional assault on one's sense of privacy.

Before concluding, we should mention two limits to the generalizability of our findings. First, the information exposed in the scenarios was never identifiable. This is not a trivial choice: the standard case for evaluating the "sense of personal violation" due to exposure can refer either to being exposed as such or to being identifiably exposed. Our choice of the former had two rationales: (1) to ensure that respondents do not consider any exposure to have potential future consequences. (2) The purpose of our study is to assess the strength of the interest in genomic privacy in a realistic context—and this refers to biobanks that present anonymous information. The relevant idea of "a sense of violation of privacy" therefore refers to conditions of anonymity. We consequently maintained this idea across all scenarios. We acknowledge that revealing identifiable information may be perceived differently in terms of breach of privacy. While we did not test this conjecture in order to maintain clarity and control in our study, it potentially limits the scope of our conclusions. Second, perceptions of privacy vary across cultures and generations. Responses to our survey do not vary systematically by age. Nonetheless, social perceptions may change as the understanding of the human genome increases and the use of such information becomes more prevalent. In a related vein, attitudes toward exposure of

genomic information may vary in non-western cultures.

In sum, the fear that publicity of genomic information as such constitutes a serious assault on privacy is not confirmed by this study. (It is worth mentioning that more than one third of respondents (54/145) rated Genome above the neutral point of 4 on the Likert scale!) This, if corroborated by further studies, should provide a measure of ethical reassurance for genomic research, as far as considerations of privacy are concerned. What this should mean precisely in practice would have to be assessed ad hoc in the fuller context of each ethical dilemma, as it arises. Beyond the context of genomic research, our assessment of the potential association between genome and personal identity may be of interest to philosophical anthropology more generally, leading us further away from the frame of thinking whereby "genes are us."

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