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Is Dupras and Bunnik's Framework for Assessing Privacy Risks in Multi-Omic Research and Databases Still Too Exceptionalist?

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OVERCOMING GENOMIC EXCEPTIONALISM IN NORMATIVE DEBATES NOT MERELY ON MULTI-OMIC DATA, BUT ALSO ON GENOME AND EPIGENOME EDITING

Dupras and Bunnik's (2021) strong statement against the normative approach of genetic exceptionalism, which can no longer be justified in the midst of multi-omic research, is of great importance for sound ethical reasoning about omic data. Furthermore, the authors' explicit critique of a sole focus on genomics in normative considerations about data security and especially their nuanced depiction of sensitivity, (re)identification risks and discriminatory potential associated with epigenomic data in research (Dupras and Bunnik 2021) and in private, commercial so-called "direct-to-consumer" epigenetic testing (Dupras, Beauchamp, and Joly 2020) might be a stepping stone for broadening the scope of normative discussions in other gene-ethics debates. Debates about therapeutic applications of tools such as CRISPR/Cas for example currently focus primarily on the genome and not on potential applications and ethical consequences of epigenome editing (Alex and Winkler n.d). Overcoming an exceptional focus on genomics and genetics by including the role of epigenomics into a primarily genome-centered normative debate is necessary to accommodate evolving biomedical fields of research.

This being said, research on epigenomics including large epigenomic datasets and epigenome editing alike is but one kind of omics going currently rather unnoticed by normative analyses. Therefore, research that highlights the ethical importance of epigenomic data (Dupras and Bunnik 2021) and of epigenome editing (Alex and Winkler n.d; WHO Expert Advisory Committee on

Developing Global Standards for Governance and Oversight of Human Genome Editing 2021; Zeps et al. 2021) is always at risk of reductionism and of replacing genomic exceptionalism, that is, "the view that genomic information deserves special attention in ethics guidelines, laws and politics" (Dupras and Bunnik 2021, 49) and the view of "reserving disproportionate ethical sensibility and scrutiny to these data types at the expense of others" (Dupras and Bunnik 2021, 58), with genomic–epigenomic exceptionalism, a view that places special attention to genomic and epigenomic data alike.

Dupras and Bunnik aim at avoiding that risk by describing their approach as "*multi-omic contextualism*" (Dupras and Bunnik 2021, 49) and by encouraging researchers from other omics fields to comment on their framework (Dupras and Bunnik 2021). According to our interpretation, the three steps of the framework indeed appear to be applicable to other than genomic and epigenomic and to non-omic data. For example, magnetic resonance imaging data that are just as genomic and increasingly epigenomic data stored in clinical and research data depositories have an "observable phenotype-relatedness" (data property i of Dupras and Bunnik 2021) because of their facial recognition potential (Prior et al. 2009).

ARGUMENTATIVE FRAMING OF DUPRAS AND BUNNIK'S FRAMEWORK

As argued above, regarding the argumentative framing of Dupras and Bunnik's highly relevant ideas "toward" (Title) a multi-omics framework, it becomes on the one hand clear that the authors indisputably intend to

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distance themselves from genetic exceptionalism, and on the other hand that the three steps of their framework are applicable to more than just genomics and epigenomics since the ten data properties listed are also applicable to non-genomic and epigenomic data. However, the ideas for a “pan-omic framework for assessing privacy risks in the multi-omic era” (Dupras and Bunnik 2021, 50) in the current framework are developed primarily from an analysis of genomics and epigenomics and might therefore still be overly focused on genomics, and epigenomics in particular (“focus [...] is on epigenomics”; Dupras and Bunnik 2021, 47).

This can be seen to imply that the framework which aims to overcome genetic exceptionalism is based in part on epigenetic exceptionalism and possibly even on epigenetic determinism, thus representing a continuation of genetic determinism in disguised form—for a clarification of the terms of genetic and epigenetic exceptionalism and determinism cf. Alex and Winkler (2021), Alex and Winkler (n.d.), and Waggoner and Uller (2015).

We further elaborate on these conceptual and argumentative considerations by explaining why, as we understand the article, it is neither pan-omic nor is it “multi-omic contextualism,” and by asking whether the framework is normative.

WHY DUPRAS AND BUNNIK’S FRAMEWORK IS NOT PAN-OMIC AND NOT MULTI-OMIC CONTEXTUALISM

The authors do not explicitly state that their framework is pan-omic but rather that it might be applicable to all (the Greek *pan* meaning *all*) omics. It is therefore not yet pan-omic, as the authors themselves acknowledge. However, the current framework cannot be described as “multi-omic contextualism” either. Instead, it would be more suitable to describe an approach which is “[b]ased on [an] analysis [...] of privacy concerns in genomics and epigenomics” (Dupras and Bunnik 2021, 55; cf. also with a specific focus on epigenetics Dupras et al. 2018; Dupras, Beauchamp, and Joly 2020), that is, on the analysis of only two (Greek *di*) omics, as di-omic (genomic-epigenomic), or even post-genomic (Guttinger 2020), a term Dupras and Bunnik (2021) reject for their framework (Dupras and Bunnik 2021).

Rather than a contextualism approach, the framework appears to be an exceptionalism approach because contextualism necessitates the consideration of extrinsic factors Dupras and Bunnik explicitly exclude from their evaluation as a context (Garrison et al. 2019). Furthermore, multi-omics as it seems to be understood by the authors necessarily requires the consideration of

extrinsic factors, that is, context, as well, as the term *multi-omics* is obviously used in the article in a rather symbolic and rhetoric than literal way and thus is not denoting the multitude of omics data but rather the fact that omics data is “multi-sectoral” and “multi-jurisdiction data”, and that “data multiplication” and “unprecedented diversification of omic data (data multiplicity)” (Dupras and Bunnik 2021, 57) exists, that is, that omics data exists in the context of multiple external factors. This might complicate the task of clear differentiation between *multi-omics* and *pan-omics*, the latter literally referring to all of omics, the former to a combination of at least two omics. The framework’s naming thus suffers from a lack of conceptual clarity.

In parts, the framework might furthermore be overly deterministic with regards to an understanding of epigenetics that can not only be described as epigenetic exceptionalism, but also as epigenetic determinism (Alex and Winkler 2021), that is, the claim that it is possible to willfully (property ix) influence so-called epigenetic activation of genes through lifestyle (cf. Dupras and Bunnik 2021) and that epigenetic effects of such behavior might even be intergenerationally inheritable (Dupras and Bunnik 2021).

These conceptual problems can, however, be easily solved by a more nuanced definition and clarification of the article’s central terms (*pan-omics*, *multi-omics*, *contextualism*), by the inclusion of extrinsic factors into the framework, and by reevaluation of our briefly mentioned critique indicating that the article might include overly deterministic claims about epigenetics while being very much conscious about not including “overly deterministic understandings of genomics” (Dupras and Bunnik 2021, 54).

IS THE FRAMEWORK NORMATIVE?

The concept of epigenetic determinism probably underlies Dupras and Bunnik’s own argumentation to only some extent at most, but it is certainly highly relevant for the application of step 2 of their framework. To give an example, the assumption “Persons or institutions may be *blamed* for harming or *pressured* not to harm themselves and/or others.” (Dupras and Bunnik 2021, 53) with regards to property ix depends on the one hand on the claim of epigenetic determinism we have described above, on the other hand on the normative claim of epigenetic responsibility. Both claims cannot be substantiated by scientific data in epigenomics research to date (Alex and Winkler 2021).

The latter is undeniably a normative assumption, as are the other data properties of step 2 of the

framework. By describing these normative assumptions as risks, the authors are themselves making a normative statement, they also do so by requesting “mitigation strategies for data protection” (Dupras and Bunnik 2021, 59) that translate the framework “in practical guidance” (Dupras and Bunnik 2021, 59).

Although it is stated at the beginning that the approach does not “intend [...] to lead to more stringent data protection requirements in biological or health research” (Dupras and Bunnik 2021, 48), and later even that it “does not make any normative claims about privacy itself, that is, about the acceptability or unacceptability of privacy risks” (Dupras and Bunnik 2021, 57), apart from its descriptive value with regards to the analysis of epigenomic data, the paper is certainly normative and rightfully so.

CONCLUSION

By means of conceptual clarification especially of the term “*multi-omic* contextualism” (Dupras and Bunnik 2021, 49) it could have been shown that Dupras and Bunnik’s framework might currently be rather exceptional than contextual especially because extrinsic data properties are not primarily considered and that the framework is di-omic (genomic-epigenomic) rather than multi-omic because the meaning of *multi-omics* within the article appears to imply contextual factors. The highly relevant normative ideas on the problem of (re)identification risks and sensitivity of other than genomic, especially epigenomic, data presented by the authors are nevertheless, as Dupras and Bunnik assume (2021), likely to be relevant even beyond omics, for example, for imaging data, and it might thus be evaluated in future research whether multi-omic exceptionalism/contextualism could present a novel form of biological reductionism (Waggoner and Uller 2015), especially if primarily focused on the analysis of genomics and epigenomics. Dupras and Bunnik’s framework might then be made even stronger by making it broader.

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