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Consent insufficient for data release

In their Policy Forum "Toward unrestricted use of public genomic data" (25 January, p. 350), R. I. Amann et al. argue that once data has been cleared for release to the public domain by institutions, it should be open for use without further restrictions. However, they neglect the key point that researchers and their institutions are entrusted by research participants, funders, and others with weighing the pros and cons of public data release. By suggesting that informed consent can provide a straightforward path to data release, they overlook evidence that once people understand their options, only a little more than half opt for open data sharing, and some refuse data sharing altogether (1, 2).

This evidence further shows that some research participants have concerns that uses of their data might not fit with their norms or values or might disadvantage certain populations. Despite their openness to wide use, they do not think ethics review and informed consent are sufficient to remove restrictions on the release of sensitive human data. Simply put, informed consent is a necessary, but far from sufficient condition for data sharing (*3, 4*).

Equally important, Amann et al.'s proposal for data sharing through openaccess databases does not reflect funders' policies. Rather, funders expect and, in some cases, mandate that researchers adopt specific organizational measures to safeguard personal data. For example, the National Institutes of Health (NIH) policy on genomic data sharing explicitly requires that data generators develop genomic data sharing plans and data users submit their requests to data access committees for review (5). The imperative for adequate data governance has also been stressed by other major funding agencies, such as the Wellcome Trust Expert Advisory Group on Data Access (6).

Admittedly, poorly designed regulation can stifle legitimate genomic data sharing that promotes the public good. Regulatory frameworks do, however, serve critical purposes, including ensuring consideration of the intricate ethical, legal, social, and political concerns inherent in many aspects of science, including genomics. Amann et al.'s uncritical use of the notion of "openness" suggests that once data have been made open, their use is unaffected by structural issues such as the unequal distribution of power and influence. This is particularly problematic in cases of for-profit enterprises that are not accountable to the public (7). Although Amann et al.'s suggestions seem emancipatory and respectful of ethical concerns, their proposal overlooks the wider political economy in which data use is embedded and conflates ethics with a rather formulaic adherence to legal and institutional guidelines and consent forms.

This complex challenge cannot be solved with a single model for data sharing governance. The currently favored model of controlled-access data sharing adopted by NIH and others is far from perfect (8). Better alternatives are emerging, such as the Global Alliance for Genomics & Health's Beacon federated model for data sharing (9). We need approaches to data sharing that address, on a case-by-case basis, how public release of data affects distribution of burdens and benefits across and within populations.

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Response

Nicol et al. make insightful comments on issues related to data sharing and ethics, regulations, and imbalance of power. We largely share their concerns, and we did indeed mention some of them briefly in our Policy Forum. Our discussion pertained to all types of data, many or most of which do not include any personal information or do not involve individuals or humans in any way. For example, environmental genomics data generated through public funding should become available shortly after generation and should enjoy unrestricted usage. As we acknowledged in the Policy Forum, when it comes to personal data, issues of privacy, confidentiality, and informed consent need to be considered carefully and the best arrangements may vary on a case-by-case basis. It makes sense to anticipate these issues before data collection begins and to aim for research designs and informed consent forms that allow maximal, prompt, open use of valuable data.

We agree with Nicol *et al.* that public release of data may affect distribution of burdens and benefits across and within populations, and this is something that should be closely monitored. However, we think that usually more openness would diminish the inadvertent concentration of informational power in the hands of select for-profit enterprises that may wish to hoard data for their own advantage. Conversely, the public release of data may offer more value for the public and more widely distributed benefits of science. **Rudolf I. Amann, Shakuntala Baichoo, Benjamin J. Blencowe, Peer Bork,** Mark Borodovsky, Cath Brooksbank, Patrick S. G. Chain, Rita R. Colwell, Daniele G. Daffonchio, Antoine Danchin, Victor de Lorenzo, Pieter C. Dorrestein, Robert D. Finn, Claire M. Fraser, Jack A. Gilbert, Steven J. Hallam, Philip Hugenholtz, John P. A. Ioannidis*, Janet K. Jansson, Jihyun F. Kim, Hans-Peter Klenk, Martin G. Klotz, Rob Knight, Konstantinos T. Konstantinidis, Nikos C. Kyrpides, Christopher E. Mason, Alice C. McHardy, Folker Meyer, Christos A. Ouzounis, Aristides A. N. Patrinos, Mircea Podar, Katherine S. Pollard, Jacques Ravel, Alejandro Reyes Muñoz, Richard J. Roberts, Ramon Rosselló-Móra, Susanna-Assunta Sansone, Patrick D. Schloss, Lynn M. Schriml, João C. Setubal, Rotem Sorek, Rick L. Stevens, James M. Tiedje, Adrian Turjanski, Gene W. Tyson, David W. Ussery, George M. Weinstock, Owen White, William B. Whitman, Ioannis Xenarios *Corresponding author. Email: jioannid@stanford.edu

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TECHNICAL COMMENT ABSTRACTS

Comment on "Quantifying hot carrier and thermal contributions in plasmonic photocatalysis"

Yonatan Sivan, Joshua Baraban, Ieng Wai Un, Yonatan Dubi

Zhou *et al.* (Reports, 5 October 2018, p. 69) claim to have proven dominance of "hot" electrons over thermal effects in plasmonic photocatalysis. We identify experimental flaws that caused overestimation of the hot carrier contribution. As an alternative interpretation, we fully reproduce their data using a purely thermal Arrhenius law with a fixed activation energy and intensitydependent heating.

Full text: dx.doi.org/10.1126/science.aaw9367

Response to Comment on "Quantifying hot carrier and thermal contributions in plasmonic photocatalysis"

Linan Zhou, Dayne F. Swearer, Hossein Robatjazi, Alessandro Alabastri, Phillip Christopher, Emily A. Carter, Peter Nordlander, Naomi J. Halas Sivan *et al.* claim that the methods used to distinguish thermal from hot carrier effects in our recent report are inaccurate and that our data can be explained by a purely thermal mechanism with a fixed activation energy. This conclusion is invalid, because they substantially misinterpret the emissivity of the photocatalyst and assume a linear intensity–dependent temperature in their model that is unrealistic.

Full text: dx.doi.org/10.1126/science.aaw9545