

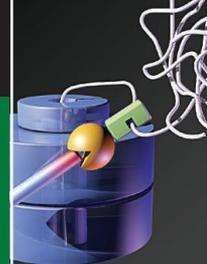
On the value of species

1035



Untangling proteins

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LETTERS | BOOKS | POLICY FORUM | EDUCATION FORUM | PERSPECTIVES

LETTERS

edited by Jennifer Sills

A Call for Integrative Thinking

IN THE 30 NOVEMBER 2012 ISSUE OF *SCIENCE*, WE WERE STRUCK by the juxtaposition of two News & Analysis stories by R. A. Kerr. One article (“Experts agree global warming is melting the world rapidly,” p. 1138) summarizes the discussions among glaciologists



about the rate at which global warming is accelerating the melting of the Greenland ice sheet, as well as the net losses of ice in Antarctica. The other (“An oil gusher in the offing, but will it be enough?,” p. 1139) analyzes the International Energy Agency’s most recent report, which shows that it is possible to meet the world’s energy demands through 2035 by drawing upon increasingly difficult-to-process oil reserves. Neither article refers to the information contained in the other. Yet, the two topics present a glaring contradiction between scientists’ concern about increasingly rapid climate change (amid World Bank warnings of the dire consequences for human well-being) and the oil industry’s preoccupation with how it can meet an undiminished world market demand for fossil fuel. If there was ever a call for the kind of problem-solving and integrative thinking that K. V. Hodges advocates in the same issue (“Solving complex problems,” Essay, p. 1164), undoubtedly this is it.

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Data Re-Identification: Prioritize Privacy

IN OUR OCTOBER 2012 REPORT, “PRIVACY and progress in whole genome sequencing” (1), the Presidential Commission for the Study of Bioethical Issues (“Bioethics Commission”) called for a consistent floor of privacy protections across state lines covering genomic data, regardless of how the data were obtained.

The need for this consistent approach to privacy protections is now more urgent than ever in light of recent advances that demonstrate the limits of genomic deidentification (“Identifying personal genomes by surname inference,” M. Gymrek *et al.*, Reports, 18 January, p. 321), which challenge obtaining the benefits of genomic data sharing (“The complexities of genomic identifiability,” L. L. Rodriguez *et al.*, Policy Forum, 18 January, p. 275).

The promise of genomic technologies will not be realized if individuals are unwilling to share their sensitive data with

the research community because of privacy concerns, or if those who share their data later discover that their privacy was invaded without their informed consent. The decline in scientists’ abilities to keep personal data “deidentified” threatens to further erode public confidence around the privacy of unique genomic data.

A “deidentified” genome has become a spectrum of possibilities for re-identification, rather than an absolute protection against privacy invasion. It therefore is incumbent on clinicians and researchers to obtain informed consent before any whole-genome sequencing and to develop and enforce appropriate limits on access to and use of all genomic data. In addition to strengthening consent and security standards, we need to streamline and strengthen laws governing the collection and use of whole-genome sequence data.

The identification of purportedly “deidentified” genomic data is no longer merely conceivable, it is already occurring. The Bioethics Commission anticipated these advances in its report and urges the adoption of the strong baseline protections

that are critical to protecting individual privacy and data security—while also encouraging the information sharing that propels scientific and medical progress.

AMY GUTMANN

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Reference

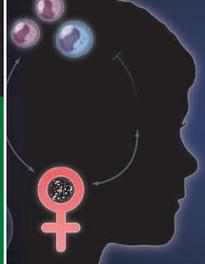
1. Presidential Commission for the Study of Bioethical Issues, “Privacy and progress in whole genome sequencing” (2012); http://bioethics.gov/cms/sites/default/files/PrivacyProgress508_1.pdf.

Data Re-Identification: Societal Safeguards

THE REPORT BY M. GYMREK *ET AL.* (“IDENTIFYING personal genomes by surname inference,” 18 January, p. 321) demonstrates that DNA samples can be combined with surname and other data to re-identify seemingly anonymous records. The study adds to the literature showing that large, publicly available data sets can be leveraged to infer personal information (1) and identify unique individuals (2). In 2005,

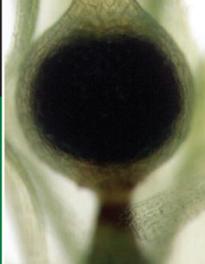
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Gender, microbes,
and disease

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Jekyll-and-Hyde
plants

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a 15-year-old tracked down his sperm donor father using a similar approach (3). This demonstration may undermine individual research subjects' confidence that their DNA can be shared in a way that is not re-identifiable. To counteract this effect, we must augment imperfect technical safeguards with measures that make such re-identification socially, legally, and economically unacceptable.

Society can work in many ways to mitigate risks and maintain a climate of confidence that will continue to encourage research subject participation. Subjects must be informed of the risk that their DNA sequence will be identified and connected to them. Data stewards must make a good-faith effort to protect DNA-based records, including continuing to deidentify the data (e.g., remove explicit identifiers). Systems for audit of access and use of the data should be routine, and data should be protected from anonymous access. Data use agreements should provide institutional and legal remedies when societal boundaries and robust research norms of respect for the privacy of individuals are violated.

The diversity of human genomes guarantees that each person will harbor markers for higher-than-average risk for some adverse outcomes. Thus, further risk mitigation should include regulatory approaches such as expansion of protections currently provided under the Genetic Information Nondiscrimination Act and other anti-discrimination laws, which currently protect against some forms of discrimination, but not others, such as long-term care or life insurance.

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References

1. K. El Emam, E. Jonker, L. Arbuckle, B. Malin, *PLoS ONE*, **6**, e28071 (2011).
2. M. A. Jobling, *Trends Genet.* **17**, 353 (2001).
3. I. Sample, "Teenager finds sperm donor dad on Internet," 2 November 2005; www.guardian.co.uk/science/2005/nov/03/genetics.news.

Data Re-Identification: Protect the Children

IN THEIR POLICY FORUM "THE COMPLEXITIES of genomic identifiability" (18 January, p. 275), L. L. Rodriguez *et al.* correctly point out that in view of the intriguing recent demonstration of the identifiability of donors participating in genomic studies ("Identifying personal genomes by surname inference," M. Gymrek *et al.*, Reports, 18 January, p. 321), the research community needs to optimize the balance between the need for data sharing and respect for the privacy of research participants.

In our 2009 *Science* Policy Forum (1), we proposed specific measures to improve the current policies and provide greater protection for children. Children are among the most vulnerable populations whose DNA samples are being collected in large numbers for epidemiologic studies. Sadly, it seems that our suggestions have not led to distinct biobanking policies for children.

We reiterate our 2009 call for the scientific research community to agree on extra safeguards, particularly restrictions on sharing

the individual genome sequences of children, unless they are contacted again as adults and provide their own consent at that time. In the case of fatal pediatric disease research (when obtaining adult and consented donor samples is implausible), conditions for sharing the personal genome sequences of children could be eased. In spite of the current genetic non-discrimination legislation widely enacted, our duty remains to ensure extra privacy protections for children, balanced with the need to continue research on pediatric diseases.

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Reference

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TECHNICAL COMMENT ABSTRACTS

Comment on "Lethally Hot Temperatures During the Early Triassic Greenhouse"

N. Goudeband, C. Romano, A. Brayard, P. A. Hochuli, H. Bucher

Sun *et al.* (Reports, 19 October 2012, p. 366) reconstructed Permian to Middle Triassic equatorial seawater temperatures. After correct temporal positioning of their data points, their presumed trends of temperature changes, and hence their assumption of a one-to-one relationship between putative "lethally hot" seawater temperatures and a disputable equatorial "eclipse" of some organisms, are no longer supported by their data. Full text at <http://dx.doi.org/10.1126/science.1232924>

Response to Comment on "Lethally Hot Temperatures During the Early Triassic Greenhouse"

Yadong Sun, Michael M. Joachimski, Paul B. Wignall, Chunbo Yan, Yanlong Chen, Haishui Jiang, Lina Wang, Xulong Lai

Goudeband *et al.* replot a subset of our well-constrained data using a new Early Triassic biostratigraphic scheme based on a lower-resolution ammonoid zonation scheme and hypothetical ammonoid-conodont correlation to produce a less distinct seawater temperature history. We dispute their unsubstantiated correlation and, consequently, their allegations.

Full text at <http://dx.doi.org/10.1126/science.1233090>

CORRECTIONS AND CLARIFICATIONS

Perspectives: "Toward molecular-scale MRI" by P. Hemmer (1 February, p. 529). The caption should say "a single NV inside a diamond nanocrystal is used to image a ribosome in the act of translation inside a live cell." A ribosome translates genetic information; it does not transcribe it. The HTML and PDF versions online have been corrected.

News & Analysis: "Final report on Stapel also blames field as a whole" by M. Enserink (7 December 2012, p. 1270). The story incorrectly stated that the committee that investigated another social psychologist, Dirk Smeesters of Erasmus University in Rotterdam, looked at only three of Smeesters' papers. The panel applied a statistical test based on work by Uri Simonsohn to experiments in every paper for which Smeesters had control over the data and to which the test was applicable—a total of 22 experiments in 10 papers. Simonsohn's test suggested data manipulation in three papers, which were investigated in more detail. The committee also investigated data files for two studies and found both to be suspicious. The HTML version online has been corrected.

Letters to the Editor

Letters (~300 words) discuss material published in *Science* in the past 3 months or matters of general interest. Letters are not acknowledged upon receipt. Whether published in full or in part, Letters are subject to editing for clarity and space. Letters submitted, published, or posted elsewhere, in print or online, will be disqualified. To submit a Letter, go to www.submit2science.org.