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 **Book** Document 1

Schramm, Katharina; Skinner, David; and Rottenburg, Richard, eds.

IDENTITY POLITICS AND THE NEW GENETICS: RE/CREATING CATEGORIES OF DIFFERENCE AND BELONGING

New York: Berghahn Books, 2012. 221 p.

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 **Article** Document 2

Lins, Tulio C; Vieira, Rodrigo G; Abreu, Breno S; Gentil, Paulo; Moreno-Lima, Ricardo; Oliveira, Ricardo J; Pereira, Rinaldo W

Genetic heterogeneity of self-reported ancestry groups in an admixed Brazilian population.

Journal of epidemiology / Japan Epidemiological Association 2011 Jul 5; 21(4): 240-5

Abstract: Population stratification is the main source of spurious results and poor reproducibility in genetic association findings. Population heterogeneity can be controlled for by grouping individuals in ethnic clusters; however, in admixed populations, there is evidence that such proxies do not provide efficient stratification control. The aim of this study was to evaluate the relation of self-reported with genetic ancestry and the statistical risk of grouping an admixed sample based on self-reported ancestry.

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 **Article** Document 3

McGuire, Amy L; Basford, Melissa; Dressler, Lynn G; Fullerton, Stephanie M; Koenig, Barbara A; Li, Rongling; McCarty, Cathy A; Ramos, Erin; Smith, Maureen E; Somkin, Carol P; Waudby, Carol; Wolf, Wendy A; Clayton, Ellen Wright

Ethical and practical challenges of sharing data from genome-wide association studies: the eMERGE Consortium experience.

Genome research 2011 Jul; 21(7): 1001-7

Abstract: In 2007, the National Human Genome Research Institute (NHGRI) established the Electronic MEDical Records and GENomics (eMERGE) Consortium ([www.gwas.net](#)) to develop, disseminate, and apply approaches to research that combine DNA biorepositories with electronic medical record (EMR) systems for large-scale, high-throughput genetic research. One of the major ethical and administrative challenges for the eMERGE Consortium has been complying with existing data-sharing policies. This paper discusses the challenges of sharing genomic data linked to health information in the electronic medical record (EMR) and explores the issues as they relate to sharing both within a large consortium and in compliance with the National Institutes of Health (NIH) data-sharing policy. We use the eMERGE Consortium experience to explore data-sharing challenges from the perspective of multiple stakeholders (i.e., research participants, investigators, and research institutions), provide recommendations for researchers and institutions, and call for clearer guidance from the NIH regarding ethical implementation of its data-sharing policy.

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Article Document 4

Ehler, Edvard; Vane, Daniel; Stenzl, Vlastimil; Vancata, Václav

Y-chromosomal diversity of the Valachs from the Czech Republic: model for isolated population in Central Europe.

Croatian medical journal 2011 Jun; 52(3): 358-67

Abstract: To evaluate Y-chromosomal diversity of the Moravian Valachs of the Czech Republic and compare them with a Czech population sample and other samples from Central and South-Eastern Europe, and to evaluate the effects of genetic isolation and sampling.



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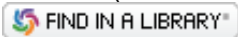


Article Document 5

Hayes, Vanessa

Indigenous genomics.

Science (New York, N.Y.) 2011 May 6; 332(6030): 639



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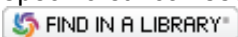
Article Document 6

de Vries, Jantina; Bull, Susan J; Dumbo, Ogobara; Ibrahim, Muntaser; Mercereau-Puijalon, Odile; Kwiatkowski, Dominic; Parker, Michael

Ethical issues in human genomics research in developing countries.

BMC medical ethics 2011 March 18; 12: 5

Abstract: Genome-wide association studies (GWAS) provide a powerful means of identifying genetic variants that play a role in common diseases. Such studies present important ethical challenges. An increasing number of GWAS is taking place in lower income countries and there is a pressing need to identify the particular ethical challenges arising in such contexts. In this paper, we draw upon the experiences of the MalariaGEN Consortium to identify specific ethical issues raised by such research in Africa, Asia and Oceania.



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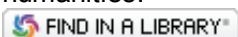
Article Document 7

Zwart, Hub; Penders, Bart

Genomics and the Ark: an ecocentric perspective on human history.

Perspectives in biology and medicine 2011 Spring; 54(2): 217-31

Abstract: Views of ourselves in relationship to the rest of the biosphere are changing. Theocentric and anthropocentric perspectives are giving way to more ecocentric views on the history, present, and future of humankind. Novel sciences, such as genomics, have deepened and broadened our understanding of the process of anthropogenesis, the coming into being of humans. Genomics suggests that early human history must be regarded as a complex narrative of evolving ecosystems, in which human evolution both influenced and was influenced by the evolution of companion species. During the agricultural revolution, human beings designed small-scale artificial ecosystems or evolutionary "Arks," in which networks of plants, animals, and microorganisms coevolved. Currently, our attitude towards this process seems subject to a paradoxical reversal. The boundaries of the Ark have dramatically broadened, and genomics is not only being used to increase our understanding of our ecological past, but may also help us to conserve, reconstruct, or even revivify species and ecosystems to whose degradation or (near) extinction we have contributed. This article explores the role of genomics in the elaboration of a more ecocentric view of ourselves with the help of two examples, namely the renaissance of Paleolithic diets and of Pleistocene parks. It argues that an understanding of the world in ecocentric terms requires new partnerships and mutually beneficial forms of collaboration and convergence between life sciences, social sciences, and the humanities.



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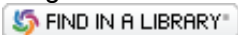
Article Document 8

Boyer, B B; Dillard, D; Woodahl, E L; Whitener, R; Thummel, K E; Burke, W

Ethical issues in developing pharmacogenetic research partnerships with American Indigenous communities.

Clinical pharmacology and therapeutics 2011 Mar; 89(3): 343-5

Abstract: Pharmacogenetic research offers the potential to improve the safety and efficacy of drug prescribing. Assuring that the benefits of this research reach indigenous and other medically underserved people is an important justice concern. First, however, a legacy of mistrust, derived from traditional research practices that disempower communities, must be overcome. Linking pharmacogenetic research to collaborative, power-sharing research partnerships provides a valuable opportunity to develop new and positive precedents for genetic research in indigenous communities.



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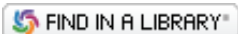
Article Document 9

Sirugo, Giorgio; Williams, Scott M; Royal, Charmaine D M; Newport, Melanie J; Hennig, Branwen J; Mariani-Costantini, Renato; Buonaguro, Franco M; Velez Edwards, Digna R; Ibrahim, Muntaser; Soodyall, Himla; Wonkam, Ambroise; Ramesar, Raj; Rotimi, Charles N

Report on the 6th African Society of Human Genetics (AfSHG) Meeting, March 12-15, 2009, Yaounde, Cameroon.

The American journal of tropical medicine and hygiene 2010 Aug; 83(2): 226-9

Abstract: The African Society of Human Genetics (AfSHG), founded in 2003 with its inaugural meeting in Accra, Ghana, has the stated missions of (1) disseminating information about human genetics research in Africa, (2) establishing a mentorship network providing educational resources, including the development of appropriate technology transfer, (3) providing advocacy for human genetic research in Africa, and (4) encouraging collaborative research. Despite its young age, the AfSHG has developed a strong cadre of active researchers, both within and outside of Africa, with more than 400 members (from 16 countries across Africa as well as 8 other countries), and has held six successful meetings, five in Africa and one in the United States.



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Article Document 10

Balter, Michael

Human genetics. Who are the Jews? Genetic studies spark identity debate.

Science 2010 June 11; 328(5984): 1342



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<http://www.sciencemag.org/content/vol328/issue5984/> (link may be outdated)



Article Document 11

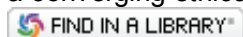
Maglo, Koffi N

Genomics and the conundrum of race: some epistemic and ethical considerations.

Perspectives in biology and medicine 2010 Summer; 53(3): 357-72

Abstract: This article addresses the question of whether race is a biological category and whether it is permissible to use it in biomedicine. I suggest that instrumentalism, a view that race is a problem-solving tool rather than a concept with an objective referent in nature, may be more consistent with the available scientific evidence. I argue that, to be morally permissible, the instrumentalist use of race in research and medicine requires stringent guidelines. I then provide four normative rules to guide race research in the biomedical sciences. The paper gathers evidence from

philosophy of science, genomics, legal history, and normative ethics in order to ground the biomedical use of race in a converging ethical and epistemic framework.



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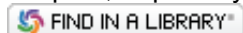
Article Document 12

Hall, Michael J

Counterpoint: implementing population genetic screening for Lynch Syndrome among newly diagnosed colorectal cancer patients--will the ends justify the means?

Journal of the National Comprehensive Cancer Network : JNCCN 2010 May ; 8(5): 606-11

Abstract: Inherited mutations in 1 of 4 known mismatch repair genes (MLH1, MSH2, MSH6, PMS2) are associated with various cancer risks collectively referred to as Lynch syndrome. Roughly 3 of every 100 new colorectal cancers (CRCs) have an underlying Lynch mutation. Tumor-based screening for Lynch among all patients with newly diagnosed CRC could theoretically improve the ability to identify Lynch and prevent cancer among at-risk family members, but the patient-level and social implications of this approach must be carefully considered before adopting this strategy. Poorly addressed issues include the role/timing of informed consent for testing, access and cost barriers associated with genetic counseling and DNA testing, psychosocial burdens to the thousands of middle-aged and elderly patients with CRC coping with surgical and chemotherapy treatments and poor prognosis, the need for providers to warn third-party relatives of risk for Lynch syndrome, limited effectiveness of screening, and the cost burden to society when poor DNA testing uptake, test limitations, and modest screening compliance are considered. Diverse barriers to the success of a population-based Lynch screening program in the United States remain (e.g., clinical resource needs, financial limitations, clinical expertise gaps, educational deficits). Data supporting clinical efficacy (feasibility) and effectiveness (real-life performance) are critical before important policy changes are adopted, especially where issues of hereditary cancer risk and genetic privacy are involved.



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Article Document 13

Loukides, Grigorios; Gkoulalas-Divanis, Aris; Malin, Bradley

Anonymization of electronic medical records for validating genome-wide association studies.

Proceedings of the National Academy of Sciences of the United States of America 2010 Apr 27; 107(17): 7898-903

Abstract: Genome-wide association studies (GWAS) facilitate the discovery of genotype-phenotype relations from population-based sequence databases, which is an integral facet of personalized medicine. The increasing adoption of electronic medical records allows large amounts of patients' standardized clinical features to be combined with the genomic sequences of these patients and shared to support validation of GWAS findings and to enable novel discoveries. However, disseminating these data "as is" may lead to patient reidentification when genomic sequences are linked to resources that contain the corresponding patients' identity information based on standardized clinical features. This work proposes an approach that provably prevents this type of data linkage and furnishes a result that helps support GWAS. Our approach automatically extracts potentially linkable clinical features and modifies them in a way that they can no longer be used to link a genomic sequence to a small number of patients, while preserving the associations between genomic sequences and specific sets of clinical features corresponding to GWAS-related diseases. Extensive experiments with real patient data derived from the Vanderbilt's University Medical Center verify that our approach generates data that eliminate the threat of individual reidentification, while supporting GWAS validation and clinical case analysis tasks.



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Article Document 14

Birenbaum-Carmeli, Daphna

Genetic relatedness and family formation in Israel: lay perceptions in the light of state policy

New Genetics and Society 2010 March; 29(1): 73-85



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<http://www.informaworld.com/smpp/title~db=jour~content=g919665103> (link may be outdated)



Article Document 15

Ledford, Heidi

Africa yields two full human genomes [news]

Nature 2010 February 18; 463(7283): 857



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<http://www.nature.com/nature/journal/v463/n7283/> (link may be outdated)

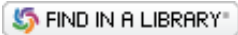


News Document 16

Wade, Nicholas

Genome study provides a census of early humans.

New York Times 2010 January 19; p. D4



<http://www.nytimes.com> (link may be outdated)



* Book Document 17

Markus, Hazel and Moya, Paula M.L., eds.

DOING RACE: 21 ESSAYS FOR THE 21ST CENTURY

New York: W.W. Norton, 2010. 590 p.

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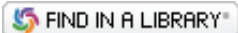


Article Document 18

Normile, Dennis

SNP study supports southern migration route to Asia. [news]

Science 2009 December 11; 326(5959): 1470



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<http://www.sciencemag.org/content/vol326/issue5959/> (link may be outdated)



Article Document 19

Gong, Yidong

Genetic finds could mean medicine tailored for communities

SciDev.Net: Science and Development Network 2009 December 11; 2 p. [Online].

Accessed: <http://www.scidev.net/en/news/genetic-finds-could-mean-medicine-tailored-for-communities-1.html> [2009 December 14]



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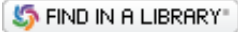


Article Document 20

Li, Ruiqiang; Li, Yingrui; Zheng, Hancheng; Luo, Ruibang; Zhu, Hongmei; Li, Qibin; Qian, Wubin; Ren, Yuangyuan; Tian, Geng; Li, Jinxiang; Zhou, Guangyu; Zhu, Xuan; Honglong, Wu; Qin, Junjie; Jin, Xin; Li, DongFang; Cao, Hongzhi, Hu, Xueda; Blanche, Hélène; Cann, Howard; Zhang, Xiuqing; Li, Songgang; Bolund, Lars; Kristiansen, Karsten; Yang, Huanming; Wang, Jun; Wang, Jian

Building the sequence map of the human pan-genome

Nature Biotechnology 2009 December 7; 7 p.



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News Document 21

Wade, Nicholas

A genetics company fails, its research too complex

New York Times 2009 November 18; p. B@



<http://www.nytimes.com> (link may be outdated)



Article Document 22

Hansson, Mats G; Maschke, Karen J.; Gurwitz, David; Fortier, Isabel; Lunshof, Jeantine E.; Knoppers, Bartha Maria

Biobanks: questioning distinctions. [letter and reply]

Science 2009 November 6; 326(5954): 797; author reply 799



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<http://www.sciencemag.org/content/vol326/issue5954/> (link may be outdated)



Article Document 23

Hens, Kristien; Wright, John; Dierickx, Kris; Gurwitz, David; Fortier, Isabel; Lunshof, Jeantine E.; Knoppers, Bartha Maria

Biobanks: oversight offers protection. [letter and reply]

Science 2009 November 6; 326(5954): 798-799; author reply 799



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<http://www.sciencemag.org/content/vol326/issue5954/> (link may be outdated)



Article Document 24

Brothers, Kyle B.; Clayton, Ellen Wright; Gurwitz, David; Fortier, Isabel; Lunshof, Jeantine E.; Knoppers, Bartha Maria

Biobanks: too long to wait for consent [letter and reply]

Science 2009 November 6; 326(5954): 798; author reply 799



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<http://www.sciencemag.org/content/vol326/issue5954/> (link may be outdated)



Article Document 25

Rose, Steven

Research into group differences isn't wrong, just pointless. [letter]

Nature 2009 November 5; 462(7269): 35



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<http://www.nature.com/nature/journal/v462/n7269/> (link may be outdated)



Article Document 26

Tadmouri, Ghazi O.; Nair, Pratibha; Obeid, Tasneem; Al Ali, Mahmoud T.; Al Khaja, Najib; Hamamy, Hanan A.

Consanguinity and reproductive health among Arabs

Reproductive Health 2009 October 8; 6(17): 1-9 [Online]. Accessed:

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2765422/pdf/1742-4755-6-17.pdf> [2011 May 27]



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Article Document 27

Genetics without borders [editorial]

Nature 2009 October 8; 461(7265): 697



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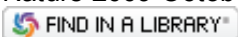


Article Document 28

Lahn, Bruce T.; Ebenstein, Lanny

Let's celebrate human genetic diversity

Nature 2009 October 8; 461(7265): 726-728



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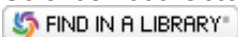


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Travis, John

Forensic science. Scientists decry isotope, DNA testing of 'nationality' [news]

Science 2009 October 2; 326(5949): 30-31



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<http://www.sciencemag.org/content/vol326/issue5949/> (link may be outdated)



Article Document 30

Freedman, Robert

Genetic investigation of race and addiction. [editorial]

American Journal of Psychiatry 2009 September; 166(9): 967-968



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News Document 31

Wade, Nicholas

Genes tied to disparity in treatment of Hepatitis C

New York Times 2009 August 17; p. A10



<http://www.nytimes.com> (link may be outdated)



Article Document 32

Gurwitz, David; Fortier, Isabel; Lunshof, Jeantine E.; Knoppers, Bartha Maria

Children and population biobanks.

Science 2009 August 14; 325(5942): 818-819



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<http://www.sciencemag.org/content/vol325/issue5942/> (link may be outdated)



Article Document 33

Obasogie, Osagie K.

Return of the race myth

New Scientist 2009 July 4-10; 203(2715): 22-23



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Article Document 34

Soo-Jin Lee, Sandra; Bolnick, Deborah A.; Duster, Troy; Ossorio, Pilar; Tallbear, Kimberly

The illusive gold standard in genetic ancestry testing

Science 2009 July 3; 325(5936): 38-39



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Article Document 35

Obasogie, Osagie

The color of our gene: balancing the promise and risks of racial categories in human biotechnology

GeneWatch 2009 July-August; 22(3-4): 25-27, 35



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Article Document 36

Duster, Tory

Ancestry testing and DNA: uses, limits-and Caveat Emptor

GeneWatch 2009 July-August; 22(3-4): 16-17, 27, 34



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Article Document 37

Ossorio, Pillar N.

Race, genes, and intelligence

GeneWatch 2009 July-August; 22(3-4): 11-13, 34



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Article Document 38

Pollack, Robert

Natural selection, the human genome, and the idea of race

GeneWatch 2009 July-August; 22(3-4): 9-11



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Article Document 39

Yudell, Michael

A short history of the race concept

GeneWatch 2009 July-August; 22(3-4): 6-9, 34



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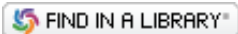


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Williams, Patricia J.

The elusive variability of race

GeneWatch 2009 July-August; 22(3-4): 4-6, 34



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United Kingdom. Academy of Medical Sciences

[Genome-wide association studies: understanding the genetics of common disease. Symposium report](#)

London: Academy of Medical Sciences, 2009 July: 31 p.

<http://www.acmedsci.ac.uk/index.php?pid=114> (link may be outdated)



News Document 42

Brown, David

Among many peoples, little genomic variety



<http://www.washingtonpost.com> (link may be outdated)



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Reid, Lynette

Networking Genetics, Populations, and Race

American Journal of Bioethics 2009 June-July; 9(6-7): 50-52



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<http://dx.doi.org/10.1080/15265160902893957> (link may be outdated)



Article Document 44

Bonham, Vence L.; Citrin, Toby; Modell, Stephen M.; Franklin, Tené Hamilton; Bleicher, Esther W.B.; Fleck, Leonard M.

Community-based dialogue: engaging communities of color in the United States' genetics policy conversation.

Journal of Health Politics, Policy and Law 2009 June; 34(3): 325-359

Abstract: Engaging communities of color in the genetics public policy conversation is important for the translation of genetics research into strategies aimed at improving the health of all. Implementing model public participation and consultation processes can be informed by the Communities of Color Genetics Policy Project, which engaged individuals from African American and Latino communities of diverse socioeconomic levels in the process of "rational democratic deliberation" on ethical and policy issues stretching from genome research to privacy and discrimination concerns to public education. The results of the study included the development of a participatory framework based on a combination of the theory of democratic deliberation and the community-based public health model which we describe as "community-based dialogue."



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Article Document 45

Gibbons, Ann

Africans' deep genetic roots reveal their evolutionary story [news]

Science 2009 May 1; 324(5927): 575



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Article Document 46

Bonham, Vence L.; Sellers, Sherrill L.; Gallagher, Thomas H.; Frank, Danielle; Odunlami, Adebola O.; Price, Eboni G.; Cooper, Lisa A.

Physicians' attitudes toward race, genetics, and clinical medicine

Genetics in Medicine 2009 April; 11(4): 279-286



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Article Document 47

Tyler, Katharine

Whiteness studies and laypeople's engagements with race and genetics

New Genetics and Society 2009 March; 28(1): 37-50



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Article Document 48

Bussey-Jones, Jada; Henderson, Gail; Garrett, Joanne; Moloney, Mairead; Blumenthal, Connie; Corbie-Smith, Giselle

Asking the right questions: views on genetic variation research among black and white research participants.

Journal of General Internal Medicine 2009 March; 24(3): 299-304



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Article Document 49

Gurwitz, David; Lunshof, Jeantine E.

Ancestry in translational genomic medicine: handle with care.

Genome Medicine 2009 February 25; 1(2): 24



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<http://genomemedicine.com/content/1/2/24> (link may be outdated)



News Document 50

Wade, Nicholas

Neanderthal genome hints at language potential but little human interbreeding

New York Times 2009 February 13; p. A12



<http://www.nytimes.com> (link may be outdated)



Article Document 51

Rose, Steven

Darwin 200: Should scientists study race and IQ? NO: Science and society do not benefit.

Nature 2009 February 12; 457(7231): 786-788



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<http://www.nature.com/nature/archive/> (link may be outdated)

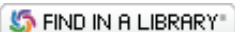


Article Document 52

Ceci, Stephen; Williams, Wendy M.

Darwin 200: Should scientists study race and IQ? YES: The scientific truth must be pursued.

Nature 2009 February 12; 457(7231): 788-789



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Article Document 53

Ilkilic, Ilhan; Paul, Norbert W.

Ethical aspects of genome diversity research: genome research into cultural diversity or cultural diversity in genome research?

Medicine, Health Care, and Philosophy 2009 February; 12(1): 25-34

Abstract: The goal of the Human Genome Diversity Project (HGDP) was to reconstruct the history of human evolution and the historical and geographical distribution of populations with the help of scientific research. Through this kind of research, the entire spectrum of genetic diversity to be found in the human species was to be explored with the hope of generating a better understanding of the history of humankind. An important part of this genome diversity research consists in taking blood and tissue samples from indigenous populations. For various reasons, it has not been possible to execute this project in the planned scope and form to date. Nevertheless, genomic diversity research addresses complex issues which prove to be highly relevant from the perspective of research ethics, transcultural medical ethics, and cultural philosophy. In the article at hand, we discuss these ethical issues as illustrated by the HGDP. This investigation focuses on the confrontation of culturally diverse images of humans and their cosmologies within the framework of genome diversity research and the ethical questions it raises. We argue that in addition to complex questions pertaining to research ethics such as informed consent and autonomy of probands, genome diversity research also has a cultural-philosophical, meta-ethical, and phenomenological dimension which must be taken into account in ethical discourses. Acknowledging this fact, we attempt to show the limits of current guidelines used in international genome diversity studies, following this up by a formulation of these designed to facilitate an appropriate inquiry and ethical evaluation of intercultural dimensions of genome research.



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Chakravarti, Aravinda

Kinship: race relations: our notions of family, population and race may need revising in the age of personal genomics

Nature 2009 January 22; 457(7228): 380-381



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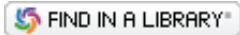
Caulfield, Timothy; Fullerton, Stephanie M.; Ali-Khan, Sarah E.; Arbour, Laura; Burchard, Esteban G.; Cooper, Richard S.; Hardy, Billie-Jo; Harry, Simrat; Hyde-Lay, Robyn; Kahn, Jonathan; Kittles, Rick; Koenig, Barbara A.; Lee, Sandra S.-J.; Malinowski, Michael; Ravitsky, Vardit; Sankar, Pamela; Scherer, Stephen W.; Séguin, Béatrice; Shickle, Darren; Suarez-Kurtz, Guilherme; Daar, Abdallah S.

Race and ancestry in biomedical research: exploring the challenges.

Genome Medicine 2009 January 21; 1(1): 8

Abstract: ABSTRACT: The use of race in biomedical research has, for decades, been a source of social controversy. However, recent events, such as the adoption of racially targeted pharmaceuticals, have raised the profile of the race issue. In addition, we are entering an era in which genomic research is increasingly focused on the nature and extent of human genetic variation, often examined by population, which leads to heightened potential for misunderstandings or misuse of terms concerning genetic variation and race. Here, we draw together the perspectives of participants in a recent interdisciplinary workshop on ancestry and health in medicine in order to explore the use of race in research issue from the vantage point of a variety of disciplines. We review the nature of the race controversy in the context of biomedical research and highlight several challenges to policy action, including

restrictions resulting from commercial or regulatory considerations, the difficulty in presenting precise terminology in the media, and drifting or ambiguous definitions of key terms.



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Yu, Joon-Ho; Goering, Sara; Fullerton, Stephanie M.

Race-based medicine and justice as recognition: exploring the phenomenon of BiDiI

CQ: Cambridge Quarterly of Healthcare Ethics 2009 January; 18(1): 57-67



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New York: Berghahn Books, 2009. 292 p.

Call number: [GN486.5 .K56 2009](#)



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EUROPEAN KINSHIP IN THE AGE OF BIOTECHNOLOGY

New York: Berghahn Books, 2009. 224 p.

Call number: [GN575 .E93 2008](#)

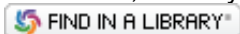


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Suda, Eiko; Macer, Darryl; Matsuda, Ichiro

Challenges to public engagement in science and technology in Japan: experiences in the HapMap Project

Genomics, Society and Policy [electronic] 2009; 5(1): 40-59



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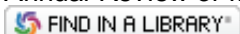


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Manolio, Teri A.; Collins, Francis S.

The HapMap and genome-wide association studies in diagnosis and therapy.

Annual Review of Medicine 2009; 60: 443-456



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Sankar, Pamela

Genetics research and race: whither bioethics?

In: Ravitsky, Vardit; Fiester, Autumn; Caplan, Arthur L., eds. The Penn Center Guide to Bioethics. New York: Springer Publishing Co., 2009: 391-402

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Kajlich, Helena

Indigenous peoples and genetic population research: reflections on a culturally appropriate model of indigenous participant consent

In: Hocking, Barbara Ann, ed. The Nexus of Law and Biology: New Ethical Challenges. Farnham, England; Burlington, VT: Ashgate Pub., 2009: 45-56

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Nelkin, Dorothy; Rosner, David

Making distinctions "natural": the science of social categorization in the United States in the twentieth century

In: Baker, Robert B.; McCullough, Laurence B., eds. The Cambridge World History of Medical Ethics. Cambridge; New York: Cambridge University Press, 2009: 643-654

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Beskow, Laura M.; Burke, Wylie

Ethical issues in genetic epidemiology

In: Coughlin, Steven S.; Beauchamp, Tom L.; Weed, Douglas L., eds. Ethics and Epidemiology. 2nd edition. Oxford; New York: Oxford University Press, 2009: 182-203

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Cunningham, Hilary

Genes, mobilities and the enclosures of capital: contesting ancestry and its applications in Iceland

In: Bamford, Sandra; Leach, James, eds. Kinship and Beyond: The Genealogical Model Reconsidered. New York: Berghahn Books, 2009: 111-137

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Patra, Prasanna Kumar; Sleeboom-Faulkner, Margaret

The Indian genomic biobank initiative and emerging bioethical issues: a community-based perspective

In: Sleeboom-Faulkner, Margaret, ed. Human Genetic Biobanks in Asia: Politics of Trust and Scientific Advancement. London; New York: Routledge, 2009: 151-167

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Kumar, Nandini K.

India's preparedness in tackling biopiracy and biobanking: still miles to go

In: Sleeboom-Faulkner, Margaret, ed. Human Genetic Biobanks in Asia: Politics of Trust and Scientific Advancement. London; New York: Routledge, 2009: 142-150

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In: Sleeboom-Faulkner, Margaret, ed. Human Genetic Biobanks in Asia: Politics of Trust and Scientific Advancement. London; New York: Routledge, 2009: 117-141

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Patenting race in a genomic age

Genomics, Society and Policy Journal [electronic] 2008 December; 4:3: 46-63



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When is 'race' a race? 1946-2003.

Studies in History and Philosophy of Biological and Biomedical Sciences 2008 December; 39(4): 437-450



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Hjörleifsson, Stefán; Árnason, Vilhjálmur; Schei, Edvin

Decoding the genetics debate: hype and hope in Icelandic news media in 2000 and 2004

New Genetics and Society 2008 December; 27(4): 377-394



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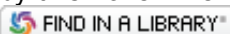
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Burns, Lawrence; Lanoix, Monique; Melnychuk, Ryan M.; Pauly, Bernie

Race, science and a novel: an interdisciplinary dialogue.

Developing World Bioethics 2008 December; 8(3): 226-234

Abstract: In the novel *Racists* by Kunal Basu (2006), two competing scientists initiate an experiment that they believe will prove which race is superior. The research subjects, one white and one black infant, are sequestered on an isolated island in the care of a mute nurse. The contest must be waged in a 'natural laboratory' with no artificial interventions and with the prospect that one will die at the hands of the other. The politics of empire, the slave trade and the advent of a new scientific way of viewing life, Darwinism, set the stage for the fictional experiment, but the ramifications of such thinking extend into the present. Coming from the disciplines of nursing, philosophy and science, we discuss how a novel can illuminate the moral dimensions of science and healthcare. The critical distance afforded by the novel provides a rich terrain for the examination of issues such as race, care and the purity of science. Despite the recent dominance of social explanations of race, science requires the examination of the differences between human beings at the biological level. The view that biology is destiny is a powerful one with dangerous consequences, especially since the belief that certain human beings' destinies are far worthier than others is a corollary of such a view. In this paper, we present the cross-disciplinary conversation, which has been facilitated by this novel. We hope this will inform ethics educators of the rich potential of using fiction as a pedagogical tool.



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Arana, Marie

He's not black

Washington Post 2008 November 30; p. B1, B4



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New Scientist 2008 November 22-28; 200(2683): 7



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The touchy subject of race [meeting report]

Science 2008 November 7; 322(5903): 839



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The case of the missing heritability. When scientists opened up the human genome, they expected to find the genetic components of common traits and diseases. But they were nowhere to be seen.

Nature 2008 November 6; 456(7218): 18-21



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Braff, Jeffrey P.; Chatterjee, Biswajit; Hochman, Meredith; Kelton, Teresa; Kennington, Jessica; Kolavala, Chandana; Layman, Katherine; Parver, Corrine; Selby, Myra C.; Washlick, John R.; Wolf, Rebecca

Patient-tailored medicine, part one: the impact of race and genetics on medicine.



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Ethics at the intersection of pharmacoethnicity.

Clinical Pharmacology and Therapeutics 2008 September; 84(3): 424-426



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Ng, P.C.; Zhao, Q.; Levy, S.; Strausberg, R.L.; Venter, J.C.

Individual genomes instead of race for personalized medicine.

Clinical Pharmacology and Therapeutics 2008 September; 84(3): 306-309



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Hartigan, John, Jr.

Is race still socially constructed? The recent controversy over race and medical genetics

Science as Culture 2008 June; 17(2): 163-193



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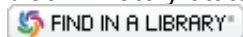
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Wensley, D.; King, M.

Scientific responsibility for the dissemination and interpretation of genetic research: lessons from the "warrior gene" controversy

Journal of Medical Ethics 2008 June; 34(6): 507-509

Abstract: This paper discusses the announcement by a team of researchers that they identified a genetic influence for a range of "antisocial" behaviours in the New Zealand M?ori population (dubbed the "warrior gene"). The behaviours included criminality, violence, gambling and alcoholism. The reported link between genetics and behaviour met with much controversy. The scientists were described as hiding behind a veneer of supposedly "objective" western science, using it to perpetuate "racist and oppressive discourses". In this paper we examine what went wrong in the dissemination of the research. We chose as our framework the debate around the "internal/external" responsibilities of scientists. Using this discourse we argue that when the researchers ventured to explain their research in terms of social phenomena, they assumed a duty to ensure that their findings were placed "in context". By "in context", we argue that evidence of any genetic influence on behavioural characteristics should not be reported in isolation, but instead presented alongside other environmental, cultural and socio-economic influences that may also contribute to the studied behaviour. Rather than imposing a new obligation on scientists, we find this duty to contextualise results is in keeping with the spirit of codes of ethics already in place. Lessons from the "warrior gene" controversy may assist researchers elsewhere to identify potential areas of conflict before they jeopardise research relationships, or disseminate findings in a manner that fuels misleading and/or potentially discriminatory attitudes in society.



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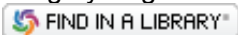
Hunt, L.M.; Megyesi, M.S.

Genes, race and research ethics: who's minding the store?

Journal of Medical Ethics 2008 June; 34(6): 495-500

Supported by: HG2299-05

Abstract: BACKGROUND: The search for genetic variants between racial/ethnic groups to explain differential disease susceptibility and drug response has provoked sharp criticisms, challenging the appropriateness of using race/ethnicity as a variable in genetics research, because such categories are social constructs and not biological classifications. OBJECTIVES: To gain insight into how a group of genetic scientists conceptualise and use racial/ethnic variables in their work and their strategies for managing the ethical issues and consequences of this practice. METHODS: In-depth semi-structured interviews were conducted with a purposive sample of 30 genetic researchers who use racial/ethnic variables in their research. Standard qualitative methods of content analysis were used. RESULTS: Most of the genetic researchers viewed racial/ethnic variables as arbitrary and very poorly defined, and in turn as scientifically inadequate. However, most defended their use, describing them as useful proxy variables on a road to "imminent medical progress". None had developed overt strategies for addressing these inadequacies, with many instead asserting that science will inevitably correct itself and saying that meanwhile researchers should "be careful" in the language chosen for reporting findings. CONCLUSIONS: While the legitimacy and consequences of using racial/ethnic variables in genetics research has been widely criticised, ethical oversight is left to genetic researchers themselves. Given the general vagueness and imprecision we found amongst these researchers regarding their use of these variables, they do not seem well equipped for such an undertaking. It would seem imperative that research ethicists move forward to develop specific policies and practices to assure the scientific integrity of genetic research on biological differences between population groups.



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Kolata, Gina

Genes explain race disparity in response to a heart drug

New York Times 2008 April 29; p. F1, F6



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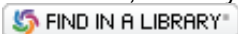


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When biology goes underground: genes and the spectre of race

Genomics, Society and Policy [electronic] 2008 April; 4(1): 23-37



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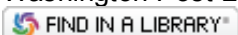


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Mui, Yan Q.

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Washington Post 2008 March 29; p. D1, D3



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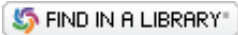


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The legitimacy of genetic ancestry tests [letter and reply]

Science 2008 February 22; 319(5866): 1039-1040



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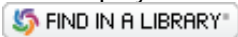


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Jefferson, NC: McFarland, 2008. 258 p.

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REVISITING RACE IN A GENOMIC AGE

New Brunswick, NJ: Rutgers University Press, 2008. 376 p.

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ETHICAL ISSUES IN GOVERNING BIOBANKS: GLOBAL PERSPECTIVES

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Ithaca, NY: Cornell University Press, 2008. 225 p.

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PROMISING GENOMICS: ICELAND AND DECODE GENETICS IN A WORLD OF SPECULATION

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Helgason, Hördur Helgi; Gibbons, Susan M.C.

Certainty is absurd: meeting information security requirements in law on population genetic databases

Medical Law International 2008; 9(2): 151-168

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Morin, Karine; Proulx, Marie-Jo

Never boring: James Watson, news and ethics

Atrium 2008; 5: 14-15



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James, Rosalina D.; Yu, Joon-Ho; Henrikson, Nora B.; Bowen, Deborah J.; Fullerton, Stephanie M.

Strategies and stakeholders: minority recruitment in cancer genetics research

Community Genetics 2008; 11(4): 241-249



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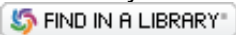


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Wenzel, Lari; Bowen, Deborah; Habbal, Rana; Leighton, Nancy; Vu, Thuy; Anton-Culver, Hoda

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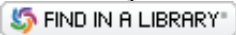


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Skinner, C.S.; Schildkraut, J.M.; Calingaert, B.; Hoyo, C.; Crankshaw, S.S.; Fish, L.; Susswein, L.; Jasper, C.; Reid, L.

Factors associated with African Americans' enrollment in a national cancer genetics registry

Community Genetics 2008; 11(4): 224-233



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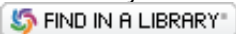


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Ramirez, Amelie G.; Miller, Alexander R.; Gallion, Kipling; San Miguel de Majors, Sandra; Chalela, Patricia; Arámburo, Sandra Garcia

Testing three different cancer genetics registry recruitment methods with Hispanic cancer patients and their family members previously registered in local cancer registries in Texas

Community Genetics 2008; 11(4): 215-223



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Patterson, Annette R.; Davis, Helen; Shelby, Kristin; McCoy, Jerry; Robinson, Linda D.; Rao, Smita K.; Banerji, Pia; Tomlinson, Gail E.

Successful strategies for increasing African American participation in cancer genetic studies: hopeful signs for equalizing the benefits of genetic medicine

Community Genetics 2008; 11(4): 208-214



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Olsen, Sharon J.; Malvern, Kathryn T.; May, Betty J.; Jenkins, Issie L.; Griffin, Constance A.

Partnership with an African American sorority to enhance participation in cancer genetics research

Community Genetics 2008; 11(4): 201-207



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Kessler, Lisa; Domchek, Susan; Stopfer, Jill; Halbert, Chanita Hughes

BRCA1 and BRCA2 risk perceptions among African American women at increased risk for hereditary breast-ovarian cancer

Community Genetics 2008; 11(4): 193-200



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Bowen, Deborah J.; Vu, Thuy; Kasten-Sportes, Carol

Increasing minority participation enrollment into a cancer family registry: the Cancer Genetics Network

Community Genetics 2008; 11(4): 191-192



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Schwartz, John

DNA pioneer's genome blurs race lines

New York Times 2007 December 12; p. A22



<http://www.nytimes.com> (link may be outdated)



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Nisbett, Richard E.

All brains are the same color

New York Times 2007 December 9; p. WK11



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Berlinger, Nancy

And I am Marie of Romania: genetics, genealogy and the ethics of storytelling

Bioethics Forum: Diverse Commentary on Issues in Bioethics [electronic] 2007 December 7; 2p.



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Kohli-Laven, Nina

Hidden history: race and ethics at the peripheries of medical genetic research

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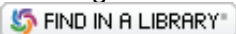


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DNA tests find branches but few roots

New York Times 2007 November 25; p. A1, A7



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New York Times 2007 November 17; p. A1, A16



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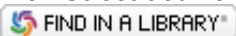


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Harvard's Gates refines genetic-ancestry searches for blacks

Wall Street Journal 2007 November 15; D5



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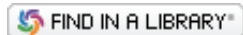


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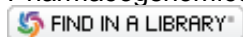


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Racial alchemy . It may not be long before genetic skin-lightening treatments are on sale, so it's time to stop pretending colour prejudice isn't a problem

New Scientist 2007 August 18-24; 195(2617): 17



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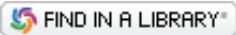
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Davis, Dena S.

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Journal of Medicine and Philosophy 2007 July-August; 32(4): 359-373

Abstract: Advances in genetic research and technology can have a profound impact on identity and family dynamics when genetic findings disrupt deeply held assumptions about the nuclear family. Ancestry tracing and paternity testing present parallel risks and opportunities. As these latter uses are now available over the internet directly to the consumer, bypassing the genetic counselor, consumers need adequate warning when making use of these new modalities.



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Sharp, Richard R.; Foster, Morris W.

Grappling with groups: protecting collective interests in biomedical research

Journal of Medicine and Philosophy 2007 July-August; 32(4): 321-337

Abstract: Strategies for protecting historically disadvantaged groups have been extensively debated in the context of genetic variation research, making this a useful starting point in examining the protection of social groups from harm resulting from biomedical research. We analyze research practices developed in response to concerns about the involvement of indigenous communities in studies of genetic variation and consider their potential application in other contexts. We highlight several conceptual ambiguities and practical challenges associated with the protection of group interests and argue that protectionist strategies developed in the context of genetic research will not be easily adapted to other types of research in which social groups are placed at risk. We suggest that it is this set of conceptual and practical issues that philosophers, ethicists, and others should focus on in their efforts to protect identifiable social groups from harm resulting from biomedical research.



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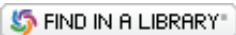


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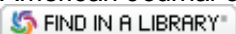


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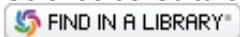


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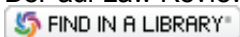


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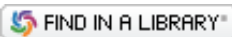


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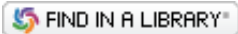


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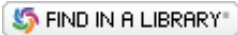


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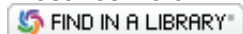


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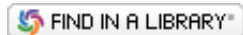


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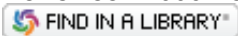


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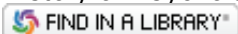


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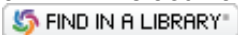


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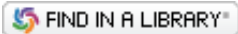


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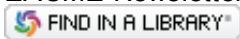


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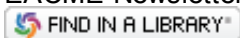


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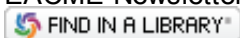


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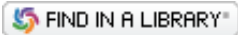


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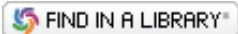


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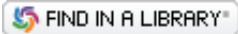


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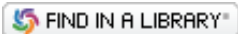


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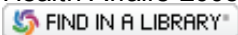


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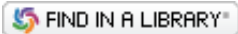
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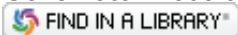


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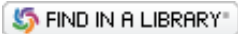


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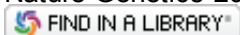


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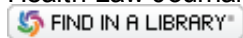


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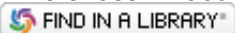


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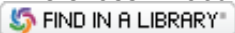


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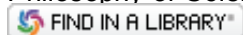


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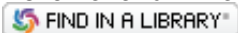


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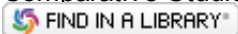


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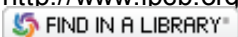
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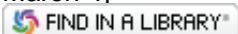


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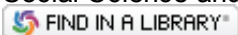


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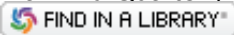


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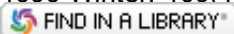


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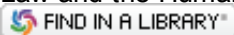
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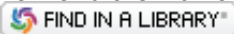


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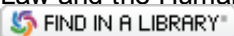


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