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Predictive Health Ethics Research (PredictER) is a multidisciplinary research, policy, and public education program of the Indiana University Center for Bioethics funded by a grant from the Richard M. Fairbanks Foundation, Inc., Indianapolis.

WEDNESDAY, APRIL 30, 2008

Predictive Health: Best Ethics Blogs - April, 2008

This issue of the "best" predictive health ethics blogs includes entries on education, eugenics, genetic counseling, genetic testing, personal genomes and privacy.

Education

More on the need for science education. Sue Trinidad, [Women's Bioethics Blog](#). 11 April 2008.

How will tomorrow's voters make informed decisions about the predictive health research and medicine. Sue Trinidad looks at the results of a recent evaluation (see: PMID: [18245328](#)) of submissions to the DNA Day essay contest for high school students; the forecast is not good. After reading comments like:

Genetics create a perfect being. Change the genes. Make that child perfect. There's no better solution to an impending health care crisis. ... What we can have is a sea of people who all look brilliant, who are all smart and who all have perfect eyes, nose and lips. It's a perfect society, what more could we want?

Trinidad calls for improved K-12 science education:

[T]hese are the responses of students who were willing to participate in an essay contest about genetics. What must be the level of understanding among those who wouldn't bother? Clearly, CLEARLY, we need to do a better job of K-12 science education.

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Eugenics?

Genetic DisEnhancement -- Does reproductive autonomy extend to choosing a disability? Linda MacDonald Glenn, [Women's Bioethics Blog](#). 13 April 2008.

Following the recent news from the UK that the government will remove references to deafness from the proposed Human Fertilisation and Embryology Bill, a decision that will permit couples to use preimplantation genetic diagnosis to select a child with congenital deafness, Glenn questions the broader implications of the decision:

My concern about removing the clause banning the creation of disabled children entirely, is why stop at deafness? Aren't the primary purposes of medicine to heal, to cure diseases, restore, and alleviate suffering? ... So the question is how far does reproductive autonomy go? Nobody wants to see a fellow human being struggle or suffer, especially in the name of 'reproductive autonomy.'

Whose Normality? D. Joy Riley, [bioethics.com](#). 17 April 2008. After reading that a economically disadvantaged couple in India accepted a child with Craniofacial Duplication as potentially a reincarnated deity, Riley wonders about Western notions of "normal" in the context of prenatal genetic diagnosis. Riley is alarmed by the concept that prenatal screening for Huntington's Disease "could eliminate this entire population!" The author asks:

Who defines 'normal'? Is normal equal to "without disease or abnormality"? If so, when? Is normal to be born without disease, or to be born with no disease or disorder present at birth, AND no genes for known disorders that will develop later in life, like breast cancer, familial polyposis of the colon, or Huntington's Disease?

Genetic Counseling

Now this is why we need genetic counselors. [SciPhu](#). 25 April 2008.

After writing (in an earlier post) that reliable predictive testing may render the job the genetic counselor obsolete, the author of SciPhu reads a paper by lead author Kimberly Quid (a

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[PredictER team](#) member). SciPhu calls the experience "eye-opening". When it comes to "high risk tests", such as a test for Huntington's Disease, SciPhu concludes:

The final take home message must be that not testing for a condition has significant value, especially when treatment options are scarce or non-existent. ... Hope is sometimes a life saver. Knowledge on the other hand, can put peoples lives in ruins.

Genetic Testing

Over-regulation. Steve Murphy, [Gene Sherpas: Personalized Medicine and You](#). 8 April 2008.

In this "follow-the-money" assessment of genomic medicine, Murphy points to the disproportionate influence of the business sector: "Genomic Medicine is being driven by business. Why? Because academia has failed to take the bull by the horns. Why? They are comfortable in their own realm. This is a stretch for them." In Murphy's view, while business sees potential money in testing, less emphasis is placed on genetic counseling and other genetic services. In the long run, however, this lopsided approach may hurt the life sciences industry. Murphy cautions that the direct-to-consumer genetic testing push may be annoying all the wrong people—some of the big names on the beltway: "AMA, ACP, SACGHS, FDA, CMS, GAO, US Senate, Department of HHS, FTC, ACMG, NHGRI..." In other words, "over regulation" may be on the way.

The gap is widening on genetic testing, too. Ricki Lewis, [blog.bioethics.net](#). 14 April 2008.

Following a post on the widening gap between public perceptions and the reality of the current state of the art in stem cell science, Ricki Lewis writes on a similar gap in the genetic testing industry. Lewis warns that whole-genome association tests may not be ready for the consumer market:

The truth is, and the direct-to-consumer company websites actually say so in the fine print ... Consumers may not be aware of these limitations, nor realize that "link," "marker," and "association," have precise scientific meanings.

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After reciting the disclaimers, Lewis doubts the services provided by 23andMe, Navigenics, and deCODEme are legitimately non-medical and asserts:

It isn't ethical to market DNA tests based on whole genome population-based studies without randomized, controlled clinical trials, replication, and validation. ... Whether considering stem cells or DNA tests, that's simply the way that good medical science is done.

The Ethics of Genetic Testing. William Martin, [Free and Wandering Thought](#). 18 April 2008.

After reporting his less than stellar performance on a recent "biopsych test", Martin shares a few free thoughts on the ethics of genetic testing for diseases like Huntington's and Bipolar disorder. Martin worries about where our society will draw the lines for the appropriate use of genetic information. Like many, he anticipates that trouble in the insurance industry and asks:

"What happens when insurance companies find out you are XX% likely to develop a disease?"

With this in mind, Martin applauds Paul Wellstone's drafted "Mental Health and Addiction Equity Act", which, as Martin reports, might have some impact on how insurance companies will (or will not) use genetic information to determine coverage for mental health disorders.

Personal Genomes and the Bioscience Industry

The Personal Genome discussion. Sandra Porter, [Discovering Biology in a Digital World](#). 24 April 2008.

Porter provides a summary of panel discussion at the University of Washington. At the event Bill Gates, Eric Lander, Maynard Olson, Leena Peltonen, and George Church fielded questions from the audience about the personal genomics revolution. Porter summarizes responses to some really interesting questions, including:

*Should people be given information about genes that are related to diseases if there's nothing that can be done?
What are options for the personal genome to benefit third world populations?*

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*How will personal genomics affect privacy?
Are we going to make designer babies?*

Also see Deepak Singh's thoughts on the discussion at [bbgm](#).

Personal Genomics Takes a Bashing on Physician Oversight, Financial Backing, and Privacy. Hsien-Hsien Lei, [Eye on DNA](#). 21 April 2008.

Lei reviews the "snarky" news coverage of the consumer genomics industry published in *Forbes* and *BusinessWeek*. While *Forbes* reports that New York's State Department of Health has sent threatening letters to some direct-to-consumer genetic testing companies ("jail-time!"), *BusinessWeek* focuses on Google's role in supporting the industry. Lei concludes: "If anyone ever organizes a biosciences startup school, they need to put regulatory affairs, investment choices, and privacy concerns on the syllabus!"

Privacy

A new model for genetic privacy: you don't have any. Daniel MacArthur, [Genetic Future](#). 20 April 2008.

After perusing a perspective piece in *Nature Reviews Genetics*, MacArthur notes that the authors call for a paradigm shift in the approach to research subject privacy, he comments: "Essentially, they argue that 'the reality of the new genetics and genomics urges us to abandon the traditional concept of medical confidentiality ...'." In MacArthur's assessment, the authors:

[A]rgue for a strategy of "maximizing data protection while informing people about its limits". In other words, doing your best to limit disclosure of individual health data, while clearly informing participants of the fact that their privacy can't be guaranteed.

Although he sees the value to the science and acknowledges the risk to privacy, MacArthur wonders how these changes might influence the future of human subjects research:

[W]ill such a policy discourage people with a clear family history of genetic disease from participating in large scale cohort studies (for insurance

reasons), thus reducing the power of such studies to detect disease-associated variants? Will it create a generation gap in research participation, with conservative older people shunning studies while the children of the Facebook era - who engage in public disclosure of information with a willfulness that seems shocking to their elders - embrace participation?

Posted by PredictER at [6:44 PM](#)



Labels: [blogs](#), [direct-to-consumer](#), [ethics](#), [eugenics](#), [genetic counseling](#), [genetic testing](#), [industry](#), [medical education](#), [privacy](#)

1 comments:

[Dana](#) said...

Wow!

What a great wrap-up.

Thanks for the inclusion.

-Steve

www.thegenesherpa.blogspot.com

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