Clin Genet 2006: 70: 445–450
Printed in Singapore. All rights reserved

CLINICAL GENETICS
doi: 10.1111/j.1399-0004.2006.00693.x

Genetic Diversity and Science Communication

Science communication in transition: genomics hype, public engagement, education and commercialization pressures

Bubela T. Science communication in transition: genomics hype, public engagement, education and commercialization pressures.
Clin Genet 2006: 70: 445–450. © Blackwell Munksgaard, 2006

This essay reports on the final session of a 2-day workshop entitled 'Genetic Diversity and Science Communication', hosted by the CIHR Institute of Genetics in Toronto, April 2006. The first speaker, Timothy Caulfield, introduced the intersecting communities that promulgate a 'cycle of hype' of the timelines and expected outcomes of the Human Genome Project (HGP): scientists, the media and the public. Other actors also contribute to the overall hype, the social science and humanities communities, industry and politicians. There currently appears to be an abatement of the overblown rhetoric of the HGP. As pointed out by the second speaker, Sharon Kardia, there is broad recognition that most phenotypic traits, including disease susceptibility are multi-factorial. That said, George Davey-Smith reminded us that some direct genotype–phenotype associations may be useful for public health issues. The Mendelian randomization approach hopes to revitalize the discipline of epidemiology by strengthening causal influences about environmentally modifiable risk factors. A more realistic informational environment paves the way for greater public engagement in science policy. Two such initiatives were presented by Kardia and Jason Robert, and Peter Finegold emphasized that science education and professional development for science teachers are important components of later public engagement in science issues. However, pressures on public research institutions to commercialize and seek industry funding may have negative impacts in both encouraging scientists to inappropriately hype research and on diminishing public trust in the scientific enterprise. The latter may have a significant effect on public engagement processes, such as those proposed by Robert and Kardia.

T Bubela

School of Business, University of Alberta, Edmonton, Alberta, Canada

Key words: commercialization – genomics – media – public engagement – public opinion – public trust – science communication – science education

Corresponding author: Tania Bubela, School of Business, University of Alberta, Edmonton, Alberta, Canada.
Tel.: +780-4929335;
fax: +780-4923325;
e-mail: tbubela@ualberta.ca

Received 4 June 2006, revised and accepted for publication 2 August 2006

In 2004, the International Human Genome Sequencing Consortium published its scientific description of the finished human genome sequence containing 20,000–25,000 protein-coding genes (1). The Human Genome Project, through political rhetoric and publicity, was portrayed as an end in itself, which, in the near term, would produce an explosion of new genomics products, services and therapeutics. Most have yet to materialize. Instead, the Human Genome Project (HGP) has proven to be one more incremental scientific advance, following well-established historical patterns.

In this essay I report on the final session of a 2-day workshop entitled 'Genetic Diversity and Science Communication', hosted by the CIHR Institute of Genetics in Toronto, April 2006. The panel was directed at key messages, policy implications and future research directions. The five speakers were Professor Timothy Caulfield, Research Director of the Health Law Institute at the University of Alberta; Jason Scott Robert from the School of Life Sciences at Arizona State University; Sharon Kardia, Director of Public Health Genetics Program at the School of Public Health at the University of Michigan; George

Davey-Smith, Head of the Epidemiology Division, University of Bristol; and Peter Finegold, Director of Public Programmes at Nowgen. The main themes emerging from the talks were the motivations of the main perpetrators of the hype surrounding the HGP, encouraging developments in science education, public participation and broader stakeholder involvement for setting science policy, and the concern that commercial pressures will further inflame the rhetoric around genomics research, putting at risk the gains in public engagement and public trust in biomedical research.

The cycle of genomics hype

The hype surrounding the HGP was promulgated by a complex set of actors, each with something to gain, who become complicit collaborators (2) in what Caulfield terms the 'cycle of hype'. Caulfield's formulation of the cycle is around three main actors, scientists, the media and the public (3). Scientists are driven partly by enthusiasm for their research and personal advancement in a highly competitive academic environment, but also by external pressures from the institutional public relations machinery, university career evaluation processes heavily geared towards research output and funding, public funding agencies, and, increasingly, industry funders.

The media, driven by their own commercial agendas, report on stories that, crudely put, will help sell papers. In the realm of genomics, outside of tragedies such as the death of Jesse Gelsinger in a premature gene therapy research trial, a number of studies have shown that the media largely act as an uncritical cheer squad for genomics research (4, 5). Scientists are regularly quoted in support of their research, sometimes making outrageous claims especially about therapeutic or product development timelines, but context setting or contrary opinions are rare. Errors in reporting of facts and basic findings are also rare, but errors of omission are common; risks are under-reported, while benefits are emphasized (4, 5). There is only limited discourse, mainly in opinion pieces, of the broader societal or ethical implications of the research. The public, therefore, receives and internalizes the message that a new age of genomics-based medicine is coming, albeit now more slowly than originally anticipated, and that genes and genetic information are important.

The public, however, cannot be considered as a homogeneous mass (6), and, as discussed in the accompanying essay on the preceding Workshop Panel by Edna Einsiedel, uses and processes the information it receives from the media in a complex manner. The public is 'a collective concept, which refers to shared efforts to achieve benefits that transcend narrow immediate personal interests and affect the community at large' (6). This notion of the public does not reduce the lay public to a set of individual consumers of genomics technologies, some of whom may have an interest in hyping genomics research to secure funding for targeted avenues of research or influence research foci. The broader public, therefore, may view the ethical and societal consequences very differently from a group of potential users of genomics products and applications.

Observations on additional offenders in the cycle of hype

Actors other than those articulated by Caulfield must also share some of the blame for the cycle of hype. The media rely almost exclusively on research published in the highest impact science and medical journals. Consequently, the editorial boards of these journals exert enormous influence over the larger genetics story being told. These biomedical journals, constrained by their own commercial pressures, emphasize positive results over negative results. Further studies refuting previously positive findings are rarely picked up by the media (7, 8).

Commercial interests also contribute significantly to the 'cycle of hype', not merely as indirect influences on scientists and media, but as independent actors. Commercial interests in the genomics sector contribute directly to the over-representation of genetic contributions to natural human variation and multi-factorial disease processes through the scramble to secure adequate venture capital and direct to consumer advertising of existing products, such as susceptibility testing, paternity testing, or testing to determine ancestral or ethnic origin for genealogy studies.

As pointed out in the workshop's concluding comments and the accompanying essay by Martin Richards, the GELS (Genomics, Ethics, Law and Society) community must also share some of the blame for the hype. Technology commentators, including social scientists, ethicists and lawyers must be cautious not to contribute to the hype. Much of the hyperbole that exists tends to focus on scientific practices which can be described as marginal at best and in the realm of science fiction at worst, for example, genetic enhancement, creation of human chimeras and even human cloning. The GELS community is caught in the same bind as the scientific community when it comes to justifying research

funding and often relies on the same sources. The GELS community has similar pecuniary and academic advancement interests in inflating the significance of ethical and societal risks from the introduction of applied genomics technologies and products. It is caught in a paradox by, on the one hand, discrediting the value or likely social benefits flowing from genomics technologies by emphasizing the speculative nature of most scientific claims and, on the other, speculating on the seriousness of all possible negative social and ethical implications of genomics research. That said, where actual products and clinical applications of genomics technologies exist, the GELS community has contributed significantly, especially in high quality empirical studies such as that of Marteau, to our understanding of the broader societal dimensions of the debate (9).

Politicians have also contributed to, and been influenced by, both negative and positive hype, and these play into parliamentary debates, which are creatures of political strategy, opportunity and compromise. Positive hype is evident in the comments made by President Clinton and Prime Minister Blair on the draft of the HGP, calling the sequence a discovery of the language God used to create life. Positive spin is common with Ministries of Industry or Science and Technology, especially in promoting the beneficial potential of biomedical research and, in effect, marketing domestic biotechnology sectors and a commercially focused research agenda.

However, negative hype is also found in political arenas, especially in controversial and marginal avenues of biomedical research. Here politicians who feel strongly about specific moral or ethical risk factors maintain a strongly oppositional stance, employing all available rhetorical devices, including exaggerating risks and the benefits of alternative research avenues, and often displaying a woeful or comical misunderstanding of the basic science. Caulfield and Bubela's analysis of the Canadian Parliamentary debates on stem cell research, for example, show that these were peppered with comments fit for publication only as science fiction. On the other hand, politicians who may be more broadly supportive of the research may disengage from the debate, unwilling to expend political capital on marginal activities with no social consensus (10).

Solutions: limits to genomics information, public engagement and science education

It seems that much of the dust has settled from the sensationalized scientific rhetoric around the HGP for the reasons discussed in Kimmelman's accompanying essay on a previous Workshop panel. Claims are now tempered by the realization that most phenotypic traits, including disease susceptibility are multi-factorial. It is likewise to be hoped that any overblown rhetoric from a minority of the GELS community will stabilize around a more realistic assessment of ethical and societal risks associated with genomics research, based on real probabilities of success or occurrence.

Like Kimmelman, I take heart in the broader contextual view of genomics as being only one contributing factor to multi-factorial disease processes, along with the environment and development. As Kardia explained in her broader view of genetic epidemiology, humans can best be described as complex biological systems functioning within, influencing and being influenced by the wider environment.

However, in some cases, there is a direct and simple link between genotype and phenotype and ironically that simple link could revitalize the maligned discipline of epidemiology. Davey-Smith reminded us that many high profile observational epidemiological studies that implicated various factors such as vitamin intake and hormone replacement therapy with positive or negative health outcomes were discredited by randomized control trials, largely because of the impossibility of teasing out or removing confounding factors such as exercise levels or smoking and problems with reverse causation. However, there is natural genetic variation in human populations where phenotypic expression can be used as a proxy for the environmentally modifiable variable of interest, while having no correlation with any of the usual confounding factors that are the downfall of so many observational epidemiological studies (11). For example, the question of whether alcohol consumption causes oesophageal cancer is confounded by the fact that drinkers smoke more and people commonly misreport their alcohol consumption. Allelic variants exist for the enzyme that metabolizes alcohol, whereby people with one form that is inefficient in clearing alcohol from the blood stream drink considerably less than efficient metabolizers. There is no association between the genotype and any potentially confounding variable, such as age, body massindex, smoking or cholesterol. However, the group of people defined by the genotype that is, on average, associated with less drinking have lower rates of oesphageal cancer than the group defined by the genotype associated with drinking more. This provides evidence that alcohol consumption itself increases the risk of oesphageal cancer and that this evidence is not vitiated

by confounding (12). Thus research utilizing genetic variants as instruments for environmentally modifiable risk factors can have considerable implications for public health epidemiology.

Also encouraging is the fact that the public seems to have relatively 'calm heads' about the hype surrounding genomics research and remains appropriately sceptical. While notoriously difficult to gauge, on the whole, polling studies have shown that the public, even in Europe, is largely supportive of biomedical research, especially when that research is perceived to be independent of industry and conducted at publicly funded research institutions (6, 13). The public has a relatively high-risk tolerance for health biotechnology applications so long as scientists are able to demonstrate the utility of their research along with a fair assessment of the risk (13). Even more encouragingly, as noted by Kimmelman and Richards in their accompanying essays, the public has not bought into an overly deterministic message. Instead, despite a decade of hype, the public retains a realistic impression of the relative contribution of genetic and environmental factors to heritable traits and disease causation.

There is a growing recognition for the need of greater public engagement in science policy. Kardia and Robert explained two such initiatives, still in their infancy, but with enormous potential to further democratize science. That 'does not mean settling questions about Nature by plebiscite, any more than democratizing politics means setting the prime rate by referendum. What democratization does mean, in science as elsewhere, is creating institutions and practices that fully incorporate principles of accessibility, transparency, and accountability. It means considering the societal outcomes of research process which involves increased accountability and transparency' (14).

Kardia's programme at the University of Michigan involves a range of activities from discussions with different faith traditions and community groups to educational modules to promote literacy and dialogue in local high schools. Robert, at the Consortium for Science, Policy, and Outcomes at Arizona State University is engaged in an ambitious initiative to give the public and other stakeholders, such as the social science and humanities communities, a greater voice in determining scientific significance and socially beneficial outcomes. Such a process recognizes the social context in which science is deeply embedded and makes transparent the value judgements that go into pursuing one line of enquiry over another. According to Robert, 'determining significance is a collaborative, even performative, enterprise to be undertaken publicly and deliberatively in spaces created and maintained for this end.' At least one of the methods to be used is Real Time Policy Assessment where social science and policy research is integrated into natural science and engineering investigations from the outset (15).

Finegold, however, reminded us that public engagement presupposes a public that is willing and able to engage and that the learning experience in High School is especially significant in laying the groundwork for later public appreciation of the science of genetics. He emphasized the importance of a relevant, stimulating and up-dated science curriculum in England and the importance of teachers in delivering that curriculum because 'good teachers matter more than good courses in inspiring children and stimulating their enthusiasm' (16). England is developing a network of Science Learning Centres where teachers can engage in Professional Development activities to maintain knowledge and skills and hopefully improve the standard of science teaching in the classroom. While the network is England-wide, the flagship national Science Learning Centre, opened by Prime Minister Blair in March 2006, is UK-wide, reflecting the remit of the key funding agencies, the English Government and the Wellcome Trust, respectively.

Some observations on public engagement models

I have a few observations to make about the broader inclusion of the public in setting scientific research agendas, which I strongly support, with a few caveats. Here, I wear my hat as a former bench/field biologist in the partly esoteric and partly applied fields of conservation biology and wildlife population genetics. First, there is an issue of scale. At the micro-scale, most basic research, and even applied research, involves those incremental steps that constitute a research or knowledge domain (17). At this level, there is little room for more than an assessment of scientific significance through the peer and ethics review processes. At the macro-scale, however, where the rise and fall of scientific knowledge domains can be mapped, the broader community has the ability to shape science policy and there is significant room for public engagement.

Second, most scientists are aware that basic research is well removed from application, let alone societal benefit. Introducing an additional layer of significance review, unless done carefully

so that it does not become one more process-oriented metric or section on a granting agency form, runs the risk of precipitating the very hype by extrapolation critiqued in the first section of this essay. Finally, unless the GELS community and scientists work harder at tempering the rhetoric and finding common ground, the public risks being caught between battling camps of would be expert arbiters of social benefit.

Will commercial realities precipitate a new hype cycle?

We were reminded by Caulfield that the above discussion must be analysed against the reality of private sector involvement (3). An important feature of the Human Genome Project was the commitment of the United States Government to transfer technology derived from the Project to the private sector (18). In Canada, Federal and Provincial governments have similarly embraced the commercialization ethos in the field of health biotechnology, in general, and genomics, in particular.

In Western countries, there is a policy push for universities and government laboratories to commercialize their research and to attract industry funding for research. For example, since 1980, the US Congress has passed no less than 80 major policy initiatives dealing with technology transfer and means of promoting it (19). The increasing pressure to commercialize raises an interesting paradox. Above, I have discussed the return to a more realistic realization that most research in genomics and related fields is basic with potential mainstream applications, distant. However, the institutional climate increasingly focused on the commercialization of research and industry funding encourages research hype.

Of greater concern is the impact of research commercialization and industry funding on public trust, the decline of which may have significant repercussions for public engagement processes. In a democratic society, it is important to maintain public trust and confidence because the lay public can exert substantial influence on their public representatives who in turn fund or regulate scientific research and the use of science-based technologies. The public is becoming increasingly suspicious of industrial influences on the research enterprise. Caulfield presented survey data that showed a perceived connection with commercial forces has an adverse impact on the perceived credibility of researchers (20, 21). A recent survey of the Canadian and US public found that publicly funded university researchers are, in the context of biotechnology, one of the most trusted and credible voices (20). However, scientists working for biotechnology companies and university researchers funded by industry were rated as one of the least credible voices. A focus group study done on behalf of the Government of Canada in 2000 came to a similar conclusion (21).

Concluding comments

One of the themes for this panel was a set of recommendations for future research directions. Given the preliminary nature of results presented by three of the speakers, there is obviously far more work to be done in developing and delivering socially relevant curricula, professional development strategies for science teachers, public engagement models, models for transdisciplinary research in developing science policy, and the impact of commercialization pressures on publicly funded research agendas, public trust and policy making.

Broader public and stakeholder engagement is a necessary improvement in science policy making. However, in the most controversial fields, there may be no social consensus. Here the challenge will be to facilitate a respectful and considered debate among stakeholder communities (and especially experts), to reach compromise without escalating hype.

Acknowledgements

I wish to thank Timothy Caulfield, Jason Scott Robert, Sharon Kardia, George Davey-Smith and Peter Finegold whose presentations at the Institute of Genetics sponsored Genetic Diversity and Science Communication Workshop (Toronto, 2006) formed the basis of this essay. However, all opinions expressed and any errors or omissions are, of course, my own. I would also like to thank the Workshop organizers Tim Caulfield, Margaret Lock and Jennifer Jennings from CIHR Institute of Genetics. The author declares no competing financial interests.

References

1. International Human Genome Sequencing Consortium. Finishing the euchromatic sequence of the human genome. Nature 2004: 431: 931–945.
2. Ransohoff D, Ransohoff R. Sensationalism in the media: when scientists and journalists may be complicit collaborators. Eff Clin Pract 2001: 4: 185–188.
3. Caulfield T. The commercialization of medical and scientific reporting. PLoS Med 2004: 1: e38–e39.
4. Bubela T, Caulfield T. Do the print media ''hype'' genetic research? A comparison of newspaper stories and peer-reviewed research papers. CMAJ 2004: 170: 1399–1407.

5. Holtzman NA, Bernhardt BA, Mountcastle-Shah E, Rodgers JE, Tambor E, Geller G. The quality of media reports on discoveries related to human genetic diseases. Comm Genet 2005: 8: 133–144.
6. Condit C. What is 'public opinion' about genetics? Nat Rev Genet 2001: 2: 811–815.
7. Conrad P, Markens S. Constructing the 'Gay Gene' in the News: Optimism and Skepticism in the US and British Press. Health: 2001: 5: 373.
8. Petersen A. The Portrayal of Research into Genetic-Based Differences of Sex and Sexual Orientation: A Study of "Popular" Science Journals, 1980 to 1997. J Commun Inq 1999: 23: 163.
9. Marteau TM, Lerman C. Genetic risk and behavioural change. BMJ: 2001: 22: 1056–1059.
10. Bubela T, Caulfield T. When human dignity is not enough: embryonic stem cell research and human cloning in Canada. In: Einsiedel EF, ed. Emerging technologies: hindsight and foresight. Vancouver: UBC Press (in press).
11. Davey-Smith G, Ebrahim S. 'Mendelian randomization': can genetic epidemiology contribute to understanding environmental determinants of disease? Int J Epidemiol 2003: 32: 1–22.
12. Lewis S, Davey Smith G. Alcohol, ALDH2 and esophageal cancer: a meta-analysis which illustrates the potentials and limitations of a mendelian randomization approach. Cancer Epidemiol Biomarkers Prev 2005: 14: 1967–1971.
13. Gaskell G, Allum N, Bauer M et al. Biotechnology and the European public. Nat Biotechnol 2000: 18: 935–938.
14. Guston DH. Forget politicizing science. Let's democratize science! Issues Sci Technol. 2004: Fall: 25–28.
15. Guston DH, Sarewitz D . Real-time technology assessment. Technol Soc 2002: 24: 93–109.
16. House of Lords, Science and Technology Select Committee, 2001.
17. Kuhn TS. The structure of scientific revolutions, 3rd edn. Chicago: University Of Chicago Press, 1996.
18. Malinowski MJ, Littlefield N. Transformation of a research platform into commercial products. In: Caulfield T, Williams-Jones B, eds. The commercialization of genetic research: ethical, legal, and policy issues. New York: Kluwer Academic/Plenum Publishers, 1999: 29–53.
19. Bozeman B. Technology transfer and public policy: a review of research and theory. Res Policy 2000: 29: 627–655.
20. Canadian Biotechnology Secretariat, International Public Opinion Research on Emerging Technologies: Canada-U.S. Survey Results (Ottawa: Canadian Biotechnology Secretariat Industry Canada, March 2005). http://www.biostrategy.gc.ca/CMFiles/E-POR-ET_200549QZS-5202005–3081.pdf
21. Pollara and Earnscliffe Research and Communications. "Third Wave: Executive Summary (Prepared for and presented to the Biotechnology Assistant Deputy Minister Coordinating Committee (BACC), Government of Canada)." BioPortal (December 2000). http://www.biostrategy.gc.ca/english/view.asp?x = 551&all = true