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Abstract

For the historian of science the current international program aimed at mapping and sequencing the entire human genome can be a bit of a headache. The literature on the Human Genome Project (HGP) is vast and inadequate; the endeavor itself is complicated, involving many institutions and funding sources and demanding at least some technical knowledge of molecular genetics, computational biology, informatics, and medical genetics, not to mention science policy and corporate biotechnology. The project is indecently contemporary, at best eight years old. Meanwhile, genome project promoters (genomics scientists, biologists turned journalists, and actual journalists) have been producing instant histories of the HGP, complete with founding parents and eureka experiences. In these accounts, the anticipated complete map of the human genome, expected by around 2000, commonly appears as a critical medical resource that will make it possible for geneticists to understand and cure genetic disease and, indeed, almost all disease. Such bewitching promises are of course part of an established genre of political narrative that is presumably not taken too seriously, least of all by those making the claims. But they have added poignancy to the public debate, as those afflicted with genetic disease or those who fear their children will be so afflicted long for the DNA translation that will, they hope, end their cross-generational suffering.

Disciplines

Genetics and Genomics | History of Science, Technology, and Medicine | Medical Genetics

The ELSI Hypothesis

By *M. Susan Lindee**

George J. Annas; Sherman Elias (Editors). *Gene Mapping: Using Law and Ethics as Guides*. xxiv + 291 pp., figs., tables, index. New York/Oxford: Oxford University Press, 1992. \$39.95.

Daniel J. Kevles; Leroy Hood (Editors). *The Code of Codes: Scientific and Social Issues in the Human Genome Project*. x + 397 pp., figs., tables, index. Cambridge, Mass./London: Harvard University Press, 1992. \$29.95.

Marcel J. Mélançon; Raymond D. Lambert (Editors). *Le génome humain: Une responsabilité scientifique et sociale*. (Actes d'un colloque tenu dans le cadre du Congrès de l'ACFAS, à l'Université de Sherbrooke, le 22 mai 1991.) xxii + 176 pp., illus., figs., table, bibls. Sainte-Foy, Quebec: Les Presses de l'Université Laval, 1992. Can \$24.95 (paper).

Michael S. Yesley (Compiler). *Bibliography: Ethical, Legal, and Social Implications of the Human Genome Project*. [x] + 145 pp. Washington, D.C.: U.S. Department of Energy, Office of Energy Research, 1992. (Available from National Technical Information Service, U.S. Department of Commerce, 5285 Port Royal Rd., Springfield, VA 22161.) (Paper.)

For the historian of science the current international program aimed at mapping and sequencing the entire human genome can be a bit of a headache. The literature on the Human Genome Project (HGP) is vast and inadequate; the endeavor itself is complicated, involving many institutions and funding sources and demanding at least some technical knowledge of molecular genetics, computational biology, informatics, and medical genetics, not to mention science policy and corporate biotechnology. The project is indecently contemporary, at best eight years old. Meanwhile, genome project promoters (genomics scientists, biologists turned journalists, and actual journalists) have been producing instant histories of the HGP, complete with founding parents and eureka experiences. In these accounts, the anticipated complete map of the human genome, expected by around 2000, commonly appears as a critical medical resource that will make it possible for geneticists to understand and cure genetic disease and, indeed, almost all disease. Such bewitching promises are of course part of an established genre of political narrative that is presumably not taken too seriously, least of all by those making the claims. But they have added poignancy to the public debate, as those afflicted with genetic disease or those who fear their

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children will be so afflicted long for the DNA translation that will, they hope, end their cross-generational suffering.

The historian coming across such a drama may well be tempted to sit back and wait for things to calm down. But there are important problems, problems uniquely suited to the historical sensibility, raised by the HGP. The project is self-consciously historical. Its texts reflect a temporally specific understanding of human DNA as essential and profitable territory. And its social organization mirrors the contradictions and tensions of late twentieth-century science between industry, government, academia, and the public, between the United States and Japan, between Paris and Washington, between physician and patient, and between parent and child.

All of which is by way of introducing a set of four recent publications dealing with the HGP that cover a narrow piece of this territory fairly well and that, despite a superficial diversity, leave a much larger piece undisturbed. The piece of the HGP that gets most of the attention is the “ethical, legal, and social implications” of its scientific findings, and the reason for the attention is transparent. The National Institutes of Health (NIH) and the Department of Energy—the primary funding agencies for genome mapping in the United States—have each set aside 5 percent of their genome project budgets to support scholars studying the ethical, legal, and social implications (commonly abbreviated as ELSI) of the genome project. For the NIH in 1993 this came to \$5 million, and in the last four years the agencies together have spent a total of \$20 million on ELSI programs. While \$20 million does not buy much big science, it goes a long way in the world of bioethics and history. Three of the books reviewed here—those by Kevles and Hood, Annas and Elias, and Yesley—are the products of ELSI funding.

The volume edited by Daniel Kevles and Leroy Hood is probably the best available general introduction to the HGP. Thirteen contributors—six biologists, seven non-scientists—explore the project in fourteen essays focusing on its history, technology, medical meaning, and ethical and legal implications. Despite the unfortunate title, *The Code of Codes* is not entirely exegesis. Three outsiders—Ruth Cowan, Evelyn Fox Keller, and Dorothy Nelkin (I suspect gender is a relevant issue here)—provide critical perspective. Cowan attempts to balance the competing values inherent in the prenatal testing puzzle; Keller explores the shrinking role of “culture” in contemporary discourse where the self has become a biological entity; and Nelkin looks at the pervasive power of the test, genetic and otherwise, that defines normalcy in ever more restrictive terms. Virtually all these essays are clearly written, and some are riveting as literary and cultural products; two examples are former HGP director James Watson’s manifest destiny explanation of why the project must go on and Charles Cantor’s discussion of sequencing technologies, their costs and their foibles. This is, then, a useful introduction precisely because it captures both promotional and critical perspectives on the genome project.

The Kevles and Hood volume might be considered part of the “first generation” of ELSI projects—the product of the early agenda-setting conferences and speaker series (circa 1989–1990), which included a suitable mix of scholarly experts and a broad overview of the issues at hand. The next generation is exemplified by the volume edited by George Annas and Sherman Elias, which is more focused and more policy oriented. The essays are intended to provide evidence for the “ELSI hypothesis” that scientific research funding should include support for complementary research in the social sciences. And they do demonstrate the potential contributions of legal scholars, historians, bioethicists, and others to the cultural phenomenon of the HGP. Robert Proctor’s exploration of the relationship between genomics and eugenics is particularly useful, as is Victor McKusick’s straightforward but perceptive insider’s summary of the historical development of human gene mapping. Judith

Swazey offers advice to scientists (e.g., do not trivialize public concerns) based on the outcome of the recombinant DNA controversies of the 1970s. Meanwhile, the legal scholar Patricia King questions the legitimacy of allocating so much public funding to mapping genes, when improving social and environmental conditions would have more, and more immediate, effects on human health. Thomas Murray, an ethicist, even asks the social scientists if their attention to the HGP reflects its real importance or only the availability of heretofore unheard-of amounts of money.

The Canadian volume, edited by Marcel Mélançon and Raymond Lambert, features a similar mix of eighteen authors, including legal experts, ethicists, philosophers, and scientists. The genre is familiar: a collection of essays drawn from an interdisciplinary conference held in 1991, in this case by the Quebec branch of the *Mouvement Universel pour la Responsabilité Scientifique (MURS-Quebec)*. The focus is explicitly on the international genomics effort, the Human Genome Organization, or HUGO. The essays explore genetic techniques and terminology, the risks and the potential of genomics research, genetic counseling, genomics and agricultural science, genetics and the legal system, and the role of the popular press in shaping conceptions of genetic disease. In one essay Bruno LeClerc, Marcel Mélançon, Richard Gagne, and Suzanne Nootens express a certain optimism about the efficacy of citizen debate in resolving the ethical questions raised by genomics research. They also suggest that the new eugenics provoked by mapping the human genome will be more insidious than the historical eugenics because it will focus on medical care, an argument that has appeared in other forums. The book closes with a transcription of a wide-ranging debate among the contributors about the responsibilities of scientists, the meaning of genetic disease, and the problems of social tolerance and difference.

Finally, Michael Yesley's bibliography lists more than 2,600 publications that deal in some manner with the ethical, legal, and social issues raised by the HGP. This list is part of a database Yesley is developing, with Department of Energy ELSI funding, that will eventually be available on-line. Inexplicably, first names or even first initials of the authors are not listed, so that, for example, the work of Sheila Faith Weiss on German eugenics appears anonymously interspersed with that of another Weiss (unknown to me) who writes articles such as "Hot Prospect for New Gene Amplifier" for *Science News*. The inclusion of historical materials is idiosyncratic: for example, Yesley lists a few popular eugenics texts, of no particular importance, from the 1920s and 1930s; there are hundreds of others from the same era that are not mentioned. I fear that for the uninitiated this printed bibliography will be of limited use. Serious students of the HGP may find some helpful listings, but the materials are not grouped or annotated. Yesley, if queried by e-mail, will do a computer sort based on topic, author, time period, or any combination of parameters. I recommend the high-tech approach.

These books join a growing literature on the social meaning of genomics research. More ELSI-funded work is on the way—including forthcoming volumes from Marc Lappé and Tim Murphy on justice and the HGP and studies by the sociologist Stephen Hilgartner and the historians Lily E. Kay, Robert Proctor, and William Schneider. And of course, in the interest of full disclosure, there is my own ELSI-funded study, with Dorothy Nelkin, which explores images of the gene in American popular culture. What impact will such scholarly studies have on the HGP? From the perspective of some scientists, none at all. In the summer of 1993 ELSI came under fire when leading genomics scientists complained that it was funding too many academic meetings and not enough work on law and policy formulation. Among those defending ELSI was Francis Collins, current head of the National Center for Human Genome Research at the NIH. Meanwhile, Philip Pauly has described ELSI as corporate quality control in the massive biomedical research conglomerate that is the

HGP. Certainly it is a quality-control division that has already manifested some independence of mind, as those who are funded by the NIH or the Department of Energy seem to be perfectly willing to interpret the HGP as a social menace. ELSI funding has not turned its very diverse grantees into uniform champions of mapping and sequencing genes.

What the funding has done, however, is to promote the distressing general tendency to divide the project into “science” and the “implications” of that science. Officially outside the ELSI territory is the most important question of all: Is mapping the human genome a meaningful scientific priority? Some ELSI insiders have identified this as a question that ELSI grantees cannot address, since a funding agency cannot expect an objective assessment of its own activities from someone whose salary it provides. ELSI is an experiment in science funding and an indulgent nod to science studies. Yet it may appeal to leading scientists such as Watson and Collins precisely because it suggests that scientists independently generate knowledge, which knowledge is then applied in specific social settings, where it has “implications.” The ELSI program, despite all its good works, effectively encodes expectations about science that have long since ceased to be compelling to historians—which is part of the reason, I would suggest, that historians have so much to contribute to the ongoing debate.