SOCIAL IMPLICATIONS OF THE HUMAN GENOME PROJECT:
POLICY ROUNDTABLE SERIES AND JOURNALS

FINAL PROGRESS REPORT
MARCH 15, 2001 - MARCH 15, 2002

Erica Seiguer

Harvard Medical School
Boston, Massachusetts

December 2002

Prepared for:

THE US DEPARTMENT OF ENERGY
AWARD NUMBER: DE-FG02-01ER63101

 agreguer
DISCLAIMER

This report was prepared as an account of work sponsored by an agency of the United States Government. Neither the United States Government nor any agency thereof, nor any of their employees, makes any warranty, express or implied, or assumes any legal liability or responsibility for the accuracy, completeness, or usefulness of any information, apparatus, product, or process disclosed, or represents that its use would not infringe privately owned rights. Reference herein to any specific commercial product, process, or service by trade name, trademark, manufacturer, or otherwise does not necessarily constitute or imply its endorsement, recommendation, or favoring by the United States Government or any agency thereof. The views and opinions of authors expressed herein do not necessarily state or reflect those of the United States Government or any agency thereof.
DISCLAIMER

Portions of this document may be illegible in electronic image products. Images are produced from the best available original document.
This report reflects the activities of the Harvard Health Caucus at Harvard Medical School that were supported, in part, by the Department of Energy.


As you know, the series began on 20 February 2001 with an address by Francis Collins, Director of the National Human Genome Research Institute at the National Institutes of Health. The talk was very well attended, with a crowd estimated at around 600 students, faculty and members of the community. Although we had reserved a large auditorium and two additional rooms with simulcast capability, we were unfortunately still over-capacity!

In the weeks following the Collins lecture, we had exciting discussions on genetic privacy, commercialization of the genome and the impact on academia-industry relationships, the genome project and its impact on the patient-doctor relationship, the role of the media in telling the story of advances in genetics to the public, and the view of various religious traditions on applications of the genome project. In addition, we arranged a screening of the movie GATTACA at the Harvard Film Archive, with a pre-movie lecture and discussion. Videos of several of the talks are available on our website.

We were very much impressed with the number of attendees, the diversity of background and training, as well as everyone’s interest in topics that fell out of their primary area of training. This diversity was evidenced by the questions raised by attendees, as well as the comments we received on the evaluation forms for each talk. Based on these forms and the traffic on our website, we have been able to generate an extensive mailing list of individuals from Harvard and beyond, who are interested not only in attending future series, but in being involved in a more in-depth manner with the Caucus. One of our greatest challenges in the coming years will be to capitalize on this enthusiasm and commitment and to build on the success of the Caucus.

Spring 2002 Policy Roundtable Series: Managing Globalization to Improve Health

The phenomenon of globalization - a process resulting from political and economic changes leading to the flow of capital across national boundaries and the liberalization of trade rules - has profoundly influenced almost every aspect of human activity today, including politics, economics, science, law, religion, culture, and health. The ability of nations to mount effective policies to both domestic and international challenges has been constrained by the process of globalization, represented by international trade agreements (GATT, NAFTA), the increasing prominence of multinational lending agencies (World Bank, IMF) and philanthropies, and the worldwide dissemination of information via the Internet. The ambivalent consequences of globalization have prompted organized resistance at times, but nonetheless promise great benefits and important opportunities.

The Harvard Health Caucus will explore how these changes have influenced health and health policy. Under globalization, health concerns that were once addressed nationally are increasingly acknowledged as problems that must be addressed through multinational collaborative efforts. Infectious disease, for example, challenges the world in ways not seen since the pre-antibiotic era. Today, given the vastly increased number of airline
passengers and flights brought about by the expansion of the world economy under globalization, an individual with a multi-drug resistant strain of tuberculosis can easily fly from the capital of Peru to New York City in less than 24 hours. Thus, local policy makers are forced to integrate international health concerns into their domestic public health strategies. HIV/AIDS in the developing world, patent laws as they effect access to medications, and clinical trials are other examples of the many health concerns that have risen to global prominence and require cooperative, international solutions.

The Caucus is particularly interested in the relationship between globalization and inequalities in health. The dynamic is complex, and while the link between increasing inequalities in health and globalization is not always clear, it is obvious that the process of globalization has highlighted many pre-existing disparities in health around the globe, in some cases contributing to inequalities and in others reducing them. Variations in the distribution of antiretroviral therapies, decisions on which drugs to develop, disparate access to health-related information and technology, and wide variations in public health expenditures within the developing world are just a few aspects of the health inequalities brought into the light under globalization. It is this mix of positives and negatives that has made globalization as contentious an issue within health as it is in other domains.

Through a series of roundtable discussions the Caucus will bring together students and experts in the diverse fields that inform health policy in order to explore the impact of globalization in health and to suggest strategies for ensuring that this process reduces health inequalities. The caucus will incorporate the various disciplines of medicine, law, science, ethics, religion, art, business, public health, and education, as we examine the effects of globalization on health. Each panel will focus on a particular challenge to the global health agenda and possible approaches to its resolution. Underlying the entire series will be an attention to the theme of inequality.

Panels in the Series

13 February 2002 Keynote Address: The Globalization of Health
Harvard Medical School

- Jeffrey Koplan, MD, MPH, Director, Centers for Disease Control

Co-sponsored by:
Distinguished Lecture Series, HSPH; Abbott Laboratories
Tosteson Health Policy Lecture Series

25 February 2002 Healthier or Wealthier: Which comes first in the new global era?
The Forum, John F Kennedy School of Government

- Roberta Baskin, Senior Producer ABC News “20/20”
Traditional economic theory holds that increases in economic productivity and gross national product lead directly to improved health and health outcomes. World Bank, United Nations, and United States development policy since World War II has been driven by this essential point of view. Alternative approaches over the last several years have begun to stress that improvements in the quality of health in developing nations actually contributes to increased productivity and economic development - that health is a limiting factor in economic development. Given the realities of globalization - free movement of goods and services, free flow of capital across borders, increased communication and information via the Internet - what makes more sense: should we be investing in development to improve health or investing in health to improve development? Decisions about development strategy, policy, and the use of billions of dollars depend on a good answer to this question.

28 February 2002 The Crisis of Neglected Diseases: Creating R&D Incentives for Diseases of Developing Countries
Harvard Business School

- Lincoln Chen, Director, Global Equity Initiative, Harvard University
- Linda M. Distlerath, Vice President, Global Health Policy, Merck
- Onesmo Mpanju, Center for Biologics Evaluation Research, Food and Drug Administration
- Diana Barrett, Harvard Business School (Moderator)

Diseases such as HIV/AIDS, malaria, and tuberculosis have retarded economic and social development across the developing world. Despite the enormous disease burden, drug discovery and development targeted at infectious and parasitic diseases in poor countries has not kept pace with the great need for new medicines and vaccines. Multinational pharmaceutical, biotechnology and agriculture companies are hesitant to allocate R&D budgets toward drugs to serve this market, choosing instead to invest in R&D for health conditions that primarily affect Western populations. Alternative models of drug development and commercialization must be explored in order to address this market failure and improve stimulate R&D on diseases of great health burden. This panel will discuss various strategies in progress, addressing purchase funds, selected patent extensions and public-private partnerships.

7 March 2002 Health Care Education in the Developing World: Bridging Global and Local Health Care Practices
Harvard Graduate School of Education
The successful introduction of modern medical practices into local cultures within developing countries is dependent upon sufficient understanding of health and medicine on the part of both the provider and the patient. For example, antibiotics are maximally effective only when dispensed properly by appropriately trained personnel. Consequently, significant collaboration among local and international participants is crucial in order to alleviate a possible mismatch between drug accessibility and inappropriate administration. In order to fully succeed, however, educational programs must take into account local beliefs and customs regarding health and health care. For example, efforts to introduce typically Western methods of family planning often clash with local conceptions of family structure and power. Such discrepancies cannot be ignored in transferring and assimilating health concepts into local practice.

This panel will address the importance of education in transferring medical knowledge and technology to the developing world by asking three questions. First, when local cultural values conflict with Western healthcare ideas, how can these differences be reconciled? Second, considering that imported medical practices frequently represent novel practices from local perspectives, can educational programs be created that allow patients to make informed decisions about treatment or prevention? And, finally, when medical treatments or preventative measures rely on extended self-implementation, how can education help patients to self-administer drugs (e.g. combinative drug therapy regimes-"cocktails"-for HIV/AIDS)?

20 March 2002 Building a Legal Framework for Global Health: How can the US and UN work to reduce global disparities?
Harvard Law School
- Brook Baker - Professor, Northeastern School of Law, co-founder of Boston Global Action Network/Africa AIDS Project
- Valerie Epps, Suffolk University Law School.
- Susan Finston, Assistant Vice President, International, Pharmaceutical Research and Manufacturers Association (PhRMA)
- Edward Luck, Director of the Center on International Organization of the School of International and Public Affairs, Columbia University; Former President, United Nations Association (1984-1994)

Globalization has increased the need for countries to look beyond their borders in order to promote effective health care strategies. In accord with a more global focus, the lines of jurisdiction have been blurred as both
domestic and international forces seek a legal framework in which to provide health care. Various documents, such as the Helsinki Accords, CIOMS, and TRIPS, have sought to improve the provision of healthcare and the protection of people's health in all areas of the world. However, difficulties in establishing a legal scaffold in an international sphere have led to problems with enforcement, regulation, and promotion of these policies. Consequently, it is necessary to consider whether current laws adequately allow for-or encourage-the provision of a minimum standard of healthcare by nations, non-governmental organizations, and industries. This panel will explore the role of the US and UN in promoting legal regimes that would address inequalities in drug access and safety testing, including the establishment of international laws to ensure that countries and corporations provide greater assistance to developing countries. This panel will also examine the possible changes that could be made in the law to promote the better use of available resources to help the millions who are dying each year.

25 April 2002 The Role of Mass Media and Tobacco Control Efforts
Harvard School of Public Health

- Mary Assunta Consumers Association of Penang, Malaysia
- Eva Kralikova Assistant Professor, Charles University, Czech Republic
- Richard Daynard - Professor of Law, Northeastern University School of Law; Chairman, Tobacco Products Liability Project; and President, Tobacco Control Resource Center
- Ichiro Kawachi, Associate Professor of Health and Social Behavior, Department of Health and Social Behavior, Harvard School of Public Health (Moderator)

With the phenomenon of globalization in recent years has come an increase in the ability of the American tobacco industry to use Eastern media to influence Eastern audiences. In the past decade, United States tobacco consumption has dropped 17 percent while exports have skyrocketed 259 percent. The war against tobacco is not being won; it is being relocated. As with any other product, much of this increase in exports is the result of advertising campaigns in developing countries. Dr Gro Harlem Brundtland, WHO Director-General has described tobacco addiction as "a communicated disease communicated through advertising, promotion and sponsorship," currently causing 4.2 million deaths per year worldwide. According to a new international public opinion survey, there is overwhelming public support for tougher regulations to control tobacco. The question that now remains is of how thorough that regulation should be. Some have proposed a total ban on tobacco advertising while others have brought up the issues of free speech and impingement on free market mechanisms. This panel will explore the feasibility and efficacy of a total ban versus that of alternatives.

Working Paper Series

The Working Paper Series was published in March 2002, as the Winter/Spring 2002 edition. It is available in print and on the Caucus website and will be distributed throughout the Spring.

Website
The Caucus continued to expand its website this academic year, attempting to create a central internet location for health policy-related events taking place at Harvard University. The Caucus developed a distribution list to reach all students at all graduate campuses at Harvard, as well as community organizations and individuals.

Financial Support of the Harvard Health Caucus at Harvard Medical School
The Caucus has enjoyed the support of diverse organizations for the 2001-2002 Academic Year. The following organizations/institutions supported the Caucus:

- Center for International Development, Harvard University
- Interfaculty Program for Health Systems, Harvard University
- Provost Fund for Student Collaboration, Harvard University
- Distinguished Lecture Series/Abbott Laboratories, Harvard School of Public Health
- Healthcare and Biotech Club, Harvard Business School
- Tosteson Health Policy Lecture Series, Harvard Medical School
- Elab, Harvard Law School
- Forum, Institute of Politics, Harvard University
- Student Council, Harvard Medical School
- The Greenwall Foundation, New York, NY
- Mintz, Levin, Cohn, Ferris, Glovsky and Popeo, P.C., Boston, MA

Organization of the Harvard Health Caucus at Harvard Medical School

Erica Seiguer (HMS/GSAS)
Chair, HHC

Policy Roundtable Series Committee
Co-Chairs:
Scott Weiss (HMS)
Ralph Vetters (HMS/HSPH)

Committee members:
Mark Friedberg (HMS/KSG)
Diane Jass Ketelhut (GSE)
Susan Wee (DMS/HSPH)
Jeff Devido (HDS)
Roy Auty (HMS-DMS)
Shanaya Deboo (HBS)
Michelle Levine (HBS)
Keyne Monson (HBS)
Wendy Netter (HLS)
Sally Aaron (HBS)
Satchi Balsari, MD (HSPH)
Anh Bui (HMS)
Shelley Day (HMS)
Kelley Larrow (GSE)
Elizabeth Crane (GSE)
Derek Willis (KSG)
Raquel Reyes (KSG)
Ruth Gerson (GSAS)
Cat Livingston (HMS)
Joel Sawady (HMS)
Jocinda Mawson (HMS)

Outreach and Communications
Co-Chairs:
Jeff Devido (HDS)
Diane Jass Ketelhut (GSE)

Advisory Council
Chair:
Kalahn Taylor-Clark (GSAS)

Operations and Budget
Co-Chairs:
Erica Seiguer (HMS/GSAS)
Susan Wee (HSPH/DMS)

Public Relations
Eliana Carvalho (GSE)

Financial Administration

Carla Fujimoto, Office of Student Affairs, Harvard Medical School (Provost Fund)
Elaine Glebus, Cannon Society, Harvard Medical School (Department of Energy and Greenwall Funds)

Plans for 2002-2003 Academic Year

Student organizers met during Summer 2002 to map out the Caucus' strategy for the coming year, and develop a long-term plan for the organization.

We would like to thank the Department of Energy for their support of the Caucus.