



DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES

April 21, 1999 Meeting Minutes

Department of Health and Human Services
Public Health Service
National Institutes of Health
Council of Public Representatives
Summary Minutes

The Council of Public Representatives convened its first meeting at 8:30 a.m., Wednesday, April 21, Building 31, Conference Room 10, National Institutes of Health, Bethesda, Maryland. The meeting was open to the public.

Dr. Harold Varmus, Chairman, Council of Public Representatives, and Director, National Institutes of Health (NIH), presided.

COUNCIL MEMBERS PRESENT:

- Michael D. Anderson
- Theodore Castele
- Robin Chin
- Luz Claudio
- Melanie C. Dreher
- Pam Fernandes
- Vicki Kalabokes
- Barbara Lackritz
- Joan Lancaster
- Debra R. Lappin
- Lydia Lewis
- Roland McFarland
- Isaac Montoya
- Rosemary Quigley
- Maurice F. Rabb
- Bob Roehr
- Thomas Vaalburg
- Doug Yee

COUNCIL MEMBERS ABSENT:

- David Frohnmayer (participated in most of the meeting by speaker phone)
- Mary desVignes-Kendrick

OTHERS PRESENT:

- Public Observers (Attachment B)
- Members of Staff, NIH

INVITED SPEAKERS:

- Dr. Jim Battey, Director, *National Institute on Deafness and Other Communication Disorders, NIH*
- Dr. Steve Katz, Director, *National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH*

- Dr. Gerald Fischbach, Director, *National Institute of Neurological Disorders and Stroke, NIH*
- Dr. Claude Lenfant, Director, *National Heart, Lung, and Blood Institute, NIH*
- Dr. Pearl O'Rourke, *Office of Science Policy, NIH*, Ms. Robin Kawazoe, *Office of Science Policy, NIH*
- Dr. Alexa McCray, *National Library of Medicine, NIH*
- Dr. John Ruffin, *Office of Research on Minority Health, NIH*
- Dr. Ed Sondik, *National Center for Health Statistics, Centers for Disease Control and Prevention*
- Dr. Norman Anderson, *Office of Behavioral and Social Sciences Research, NIH*
- Dr. Otis Brawley, *National Cancer Institute, NIH*
- Dr. Michael Gottesman, Deputy Director for Intramural Research, *Office of the Director, NIH*

I. Welcome and Background on COPR

Dr. Varmus welcomed Council members, guests, and staff and announced that the Council meeting would be open to the public. He also thanked Council members for attending an orientation session on the previous day. Before beginning the group's deliberations, he addressed three preliminary questions:

1. How did this group come to be? — Several years ago, continued increases in the NIH budget led to questions about how NIH made decisions and set priorities. Although NIH addressed these questions in congressional testimony and in a booklet, the 1998 budget bill contained language calling on the Institute of Medicine (IOM), a component of the National Academy of Sciences, to conduct a study of how NIH sets priorities and interacts with the public. The report of that study, released in June 1998, contained many valuable conclusions and a number of recommendations, including Recommendation 8:

The Director of NIH should establish and appropriately staff a Director's Council of Public Representatives (COPR), chaired by the NIH Director, to facilitate interactions between NIH and the general public.

On September 23, 1998, Dr. Varmus met with a group of 23 outside advisors to discuss the creation and role of COPR, including the criteria that should be used in selecting potential members. Based on their advice, NIH advertised for and received about 250 excellent applications, which were vetted by Dr. Varmus and an outside group of advisors. At the end of the process, Dr. Varmus selected the 20 members of the COPR. Dr. Varmus also invited the remaining candidates to join as COPR Associates. This group will provide a pool of candidates from which to replace current members at the end of their terms and will be a source for ad hoc members and consultants for specific tasks and questions that arise.

2. What is COPR's role? — Dr. Varmus described two related functions for COPR: (1) to help NIH communicate with the public by describing both its strengths and its weaknesses; and (2) to bring public views to NIH at a central point; for example, by offering advice on how the 25 Institutes and Centers handle their interactions with the public. Specific duties of COPR members will include attending two meetings per year, probably in April and October; consulting with NIH on issues that may arise; and performing at least one additional task during their term, such as attending a trans-NIH budget retreat, working with the NIH Peer Review Oversight Group (PROG), participating on a committee reviewing Institute Directors, serving on the Government Performance and Results Act (GPRA) Review Committee, or assuming a leadership position with the COPR Associates program. Dr. Varmus also urged the members to express their ideas about the appropriate agenda topics and activities of the COPR.

3. What is today's agenda? — Today's activities mirror the activities of the COPR in the longer term. First, four Directors will describe how their Institutes interact with the public. Four other Institutes made similar presentations at the meeting on September 23, 1998, and thus, over the next three years, Directors of all 25 of the Institutes and Centers will have made such presentations to the COPR. Second, NIH staff will describe the important operational issue of clinical trials, and in particular patient access to trials and the creation of a government/private sector Clinical Trials Database. Third, staff will describe an important scientific initiative, how to address "health disparities" between specific domestic and international populations. Finally, Council members will be asked to comment on COPR's future agendas and activities.

II. Introduction of Council Members

Dr. Varmus requested that the Council members introduce themselves (see Attachment 1). He also introduced Anne Thomas, Director of the Office of Communications and Public Liaison, Office of the NIH Director, whose office provides staff support for COPR.

III. How the Public is Involved in NIH Activities

Dr. Jim Battey, Director of the National Institute on Deafness and Other Communication Disorders (NIDCD), explained that when his Institute was created in 1989, 35 outside organizations participated in formulating the strategic research plan that is the foundation of NIDCD's current research activities. Since then, NIDCD has solicited public views through annual or biannual workshops on topics such as research and training needs, the impact of visual impairments on persons who are deaf or hard of hearing, and the prevention of noise-induced hearing loss. In 1999, when NIDCD met to revise its strategic research plan, 200 organizations were invited to participate, of which 20 submitted written comments and 20 made oral presentations at the conference. Later this year, a public forum on the subject of informed consent for patients who are deaf or hearing impaired will be held.

NIDCD also provides information to the public on communication disorders, primarily through the NIDCD Information Clearinghouse created in 1989. The Clearinghouse collects, categorizes, and disseminates information to a variety of audiences and through a variety of media: mail, fax, and e-mail, but primarily telephone. There has been a huge increase in the number of hits to the NIDCD Web site at <http://www.nidcd.nih.gov>, rising from 9,500 in May 1996 to 172,000 in March 1999. Information products include fact sheets, pamphlets, and reprints, and NIDCD sponsors an information booth at meetings of scientific and professional societies. More recently, NIDCD (in cooperation with a coalition of groups, agencies, and organizations) is preparing to launch the WISE EARS initiative to increase public awareness of the dangers of noise-induced hearing loss.

In response to questions from Council members, Dr. Battey said that visual impairment, while properly considered a communication disorder, is primarily the responsibility of the National Eye Institute. He also said that a recent episode of the television drama "ER" had done much to raise public awareness of hearing loss in children and the availability of cochlear implants; it might be useful to ask the producers of "ER" and similar shows to advertise the NIDCD Web site at the end of such episodes. NIDCD is currently sponsoring clinical trials on the diagnosis of hearing loss in infancy and hopes to support state government programs to screen all infants. NIDCD is also collaborating with the NIH Office of Science Education to develop Web-based "curriculum enhancement projects," including one that simulates progressive hearing loss. COPR members suggested other means of disseminating information—for example, one member suggested traveling museum exhibits and another suggested that NIH develop science curricula on the Internet (possibly in collaboration with the National Science Teachers Association).

Dr. Steve Katz, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), explained that his Institute includes public members on its National Advisory Council, which reviews scientific grants and helps set policies for NIAMS. One of these public members chairs the Council's subcommittee on information dissemination. Outreach activities include a Web site, telephone clearinghouse, faxback and mailback services, and a National Osteoporosis Resource Center that is jointly supported by other Institutes. Dr. Katz meets regularly with a coalition of 55 voluntary and professional groups, as well as with individual associations and societies, and he finds their input an invaluable contribution to NIAMS outreach activities.

NIAMS also solicits input from a wide variety of audiences in its planning process, which is designed to identify research gaps and opportunities and to develop programs that will support and stimulate research in these areas. Public members of the National Advisory Council participate in the spring and summer retreats that develop initiatives for the succeeding two years, and NIAMS meets with other organizations to solicit their comments on these initiatives. The challenge now is to extend the planning horizon to three or four years, and to involve more of the Institute's various constituents in this longer-range planning process.

A COPR member complimented NIAMS on including public members on its Advisory Council and urged other Institutes to follow this example; she asked that the COPR members receive a report on how many Institutes and Centers include public members on their councils and at their retreats and how these public members are engaged. She also added that there remains a perception that NIH research is fragmented. Dr. Katz responded that NIAMS collaborates with other Institutes in areas of shared research interest, such as the intersection of osteoporosis, aging, and depression. In terms of outreach, however, the best mechanism has been workshops that involve a range of voluntary organizations, who in turn disseminate information to their constituencies. Other COPR members cautioned that many voluntary organizations may lack the manpower to be equal partners in outreach, and that the turnaround time on their newsletters is too slow to be a useful channel of communication. Dr. Katz invited all organizations to duplicate and disseminate material from the NIAMS Web site, and Dr. Varmus also invited members to visit the NIH homepage and comment on its usefulness and "user-friendliness."

Dr. Gerald Fischbach, Director of the National Institute of Neurological Disorders and Stroke (NINDS), told the Council that he appreciated this opportunity to hear how other Institutes were handling public interaction. Like them, NINDS involves the public in its workshops, and he has found them to be highly educated and aware of the latest science. The Institute is trying to involve them in study sections (the first level of grant review, primarily of the science proposed) and clinical trials review groups, as well, and he has found them particularly useful as an interface between Institutes (for example, between NINDS and the National Institute of Mental Health), as well as between NINDS and industry or voluntary organizations.

Because NINDS deals with as many as 600 different diseases, its planning process is particularly complex, as are its interactions with some 257 advocacy groups, 50 of which are highly involved in the NINDS planning process. As part of the current planning effort, public representatives are included on five of the seven cross-cutting panels that will develop the elements of a new strategic research plan, Neuroscience at the New Millennium; ten voluntary organizations reviewed the preliminary draft, and many others will review and comment on the final draft. Voluntary organizations have praised this process, which has also demonstrated that it is possible for these groups to check their special interests at the door in order to think broadly about science and disease.

In response to questions from COPR members, Dr. Fischbach added that his Institute is involved in translating experimental discoveries into clinical treatments for epilepsy, stroke, and other neurological diseases. NINDS will soon launch a public service campaign urging patients and practitioners to treat stroke as they would a heart attack, as an emergency that requires immediate treatment; this too was the subject of an "ER" episode. NINDS spends 10 percent of its budget on training, with a special emphasis on "recapturing" clinicians into research careers by challenging them to play the role of physician-scientist. Another COPR member suggested that NINDS might also support community-based outreach and education programs to promote their findings and elevate the image of biomedical researchers.

Dr. Claude Lenfant, Director of the National Heart, Lung, and Blood Institute (NHLBI), described his Institute's broad biomedical mandate. NHLBI's National Advisory Council, which meets four times a year to advise on all of its programs in research, education, and communication, includes 12 scientists and 6 public representatives. Representatives of voluntary organizations and advocacy groups also participate in developing and reviewing new initiatives in areas of scientific opportunity or need. In addition, NHLBI's Information Office responds to over 6,000 queries each month, and its Web site, <http://www.nhlbi.nih.gov>, receives 30,000 hits per month for information on cholesterol alone. Its clinical trials database receives another 28,000 hits per month, which is very helpful in recruiting subjects for clinical trials.

NHLBI has particularly long experience with education and prevention programs in areas such as blood pressure, cholesterol, asthma, and heart attack. Some 67 different organizations participate in these programs, 20 of them public-interest groups and many others community-based organizations for minority, Native American, and Latino populations. These groups can participate directly, by bringing to NHLBI's attention health problems that affect their constituencies, or indirectly, by helping NHLBI develop research programs to address those problems. A recent example is lymphangioliomyomatosis (LAM), a rare but fatal lung disease that primarily strikes young women. In 1995, a group of mothers lobbied Congress to address this disease, leading NHLBI to form a working group that included the families of LAM patients. This led to a request for applications (RFA) in 1996, and by 1999 considerable progress has been made by NIH scientists and grantees on treating and even curing the disease.

In response to questions from COPR members, Dr. Lenfant agreed that LAM was an example of how this process could empower consumers to become more involved in planning, but that in other areas there was a need to disseminate the information already in hand. In the case of asthma, for example, there continues to be an alarming increase in the incidence of the disease, despite the availability of treatment. In some places the treatment is so familiar that schoolchildren wear their inhalers like jewelry. Another member added that the situation was much the same in the case of hypertension; perhaps COPR can help NIH to increase public awareness and stimulate the creation of local support groups for this disease.

IV. Patient Access to Clinical Trials

Dr. Pearl O'Rourke, Office of Science Policy, described clinical trials as the mechanism that translates research discoveries into patient care. There are three major types of trials—therapeutic, diagnostic, and preventative—but the first two types go through a formal progression in size and complexity:

- Phase 1—to determine correct dosage and administration;
- Phase 2—to determine toxicity and safety;
- Phase 3—to determine effectiveness; and
- Phase 4—to conduct surveillance for long-term effects.

The promise of this mechanism cannot be realized, however, if there are no patients in the clinical trials, and there are indications that fewer people are entering them. There are many potential barriers to recruiting patients for clinical trials, including the physician's awareness of the trial and willingness to refer; the patient's willingness to be randomized; the willingness of the third-party payer (employer, HMO, insurer) to continue to pay for all or part of the patient's routine medical care; and the declining population base at academic health centers, the traditional source of patients for clinical trials. Money can also be a problem as some but not all of the many costs are covered by the trial's sponsor. These incremental costs are hard to quantify, but they are a concern for third-party payers.

NIH is addressing these questions. The National Cancer Institute (NCI) is sponsoring a study by the RAND Corporation to estimate the incremental costs of clinical trials, which have been estimated at anywhere from 2 percent to 5 percent. NIH is also negotiating agreements with third-party payers to cover the routine costs of medical care for patients in clinical trials. Agreements have already been signed between NCI and the Department of Defense (CHAMPUS), Veterans Administration, and a number of health plans in Wisconsin and Minnesota. NCI supports state initiatives to require such coverage in Ohio and Maryland. Arizona is considering a state law to mandate similar coverage. NIH has also signed an agreement with the American Association of Health Plans (AAHP) that recognizes the importance of clinical trials in finding better treatments and calls for partnership in finding ways to recruit and pay for the routine medical care for patients in a clinical trial; negotiations for implementation of this agreement are currently under way.

In response to questions from COPR members, Dr. O'Rourke said that some health plans, such as Kaiser Permanente and Puget Sound, already cover the routine care of patients in clinical trials. The details of the AAHP agreement are being worked out by a 13-member council, with 5 members designated by AAHP, 5 by NIH, and 3 patient advocates on whom they mutually agree. One member suggested that NIH might work with local hospitals and HMOs to advertise the availability of clinical trials; some of these organizations already see the possibility of being included in clinical trials as a marketing feature, and perhaps this approach will spread.

V. Clinical Trials Database

Robin Kawazoe of the Office of Science Policy described the proposed Clinical Trials Database as a unique resource that will provide the public with improved information and access to clinical trials, and will help NIH and others in recruiting subjects. Under section 113 of the FDA Modernization Act of 1997, the Secretary of HHS, acting through the Director, NIH, in collaboration with FDA and CDC, is required to establish, maintain, and operate a data bank of information on clinical trials (whether federally or privately funded) for drugs for serious or life-threatening diseases and conditions submitted under section 505(i) of the FD&C Act, and experimental treatments for serious or life-threatening diseases and conditions that may be available under a treatment Investigational New Drug Application under section 561(c) of the FD&C Act, or as a Group C cancer drug (as defined by the National Cancer Institute). Section 113 also specifies what information must be provided about each trial: purpose, eligibility criteria, location of trial site(s), and point of contact for further information. It also requires that the information in the database be accessible via toll-free telephone communications. The Secretary, DHHS, the Director, NIH, and the Commissioner, FDA, are required to report to Congress on the feasibility of including device investigations in the database. She also noted that this effort was an excellent example of collaboration between NIH and FDA, and that the agencies are continuing to work together in developing the database.

To develop plans for this database, NIH staff met in February 1998, in conjunction with a meeting of patient advocates, health care providers, and researchers, to discuss revamping of the NCI Clinical Trials Information System. The participants in that meeting urged that the database be as broad and as comprehensive as possible. In June 1998, representatives of the Patient Coalition recommended that NIH start with those trials and data elements required by section 113 and add any additional information at a later time. The Drug Information Association (a scientific organization of groups involved in all aspects of drug development) expressed its interest in and questions about this initiative. In November 1998, representatives of the Pharmaceutical Research and Manufacturers of America indicated their willingness to participate in providing information to the database, and also questioned how the database would be implemented. Ms. Kawazoe noted that NIH is developing a resource for the public and how important it is to obtain additional public input on the design and operation of the system that will need to serve a wide range of users. She solicited COPR's comments and suggestions.

Dr. Varmus has asked the National Library of Medicine (NLM) to take the lead role in designing and developing this system. Dr. Alexia McCray of NLM reported that a prototype will be available for testing in the summer of 1999. The goal is to get NIH clinical trials into the database by the end of 1999. The private sector and other Federal agencies will be added beginning in 2000. The system will be accessible over the World Wide Web, and is being designed for use by patients, families, other members of the public, and health care providers. Using four different scenarios, Dr. McCray described how these different groups might make use of the clinical trials information that will be available through the system. The system is envisioned as a central resource providing "one-stop shopping" for many users and situations, including hot links to additional information on the conditions of interest.

COPR members were enthusiastic about the proposed Clinical Trials Database. One of them suggested that the use of this database should be part of the nursing curriculum. Many potential patients don't have computers, however, and one COPR member expressed concern that the Internet might actually increase disparities in access to health information among different populations. For this reason, NIH may need to reach some audiences through television, talk radio, museum exhibits, and a toll-free number where someone can perform a computer search for them. NIH may also need to mount a marketing initiative to counteract the negative publicity and misinformation that can attach to clinical trials, particularly in the area of mental health.

VI. Health Disparities

Dr. Varmus introduced a panel discussion on health disparities by explaining that NIH is concerned by the question of why some individuals and groups have different health status and health outcomes than the general population. Much of this concern focuses on minority populations, but other disparities can be seen in rural, elderly, and low-income groups. To explore this question, NIH is pursuing several avenues of investigation—socioeconomic, behavioral, genetic, and educational—in order to identify the factors that influence these differences.

Dr. John Ruffin, Director of the NIH Office of Research on Minority Health, moderated the discussion. He asserted that health disparities are real and that health differences can be quantified, but that the influence of race in particular is filtered through biological, cultural, socioeconomic, and political perspectives. In fact, there is an emerging consensus that multiple factors influence the relationship between race and health status. To address these disparities, NIH has launched a major initiative to investigate international and domestic health disparities. In addition, NIH is collaborating in an HHS-wide initiative to eliminate, by the year 2010, all racial disparities in six specific areas: infant mortality, cancer, cardiovascular disease, diabetes, HIV-AIDS, and child health and adult immunization.

Dr. Ed Sondik of the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC), described the available epidemiological data on health disparities. He explained that these statistics have two uses: (1) to demonstrate that the lower risk or better outcome is achievable; and (2) to help allocate resources for identifying and testing interventions that will achieve this lower risk or better outcome in all groups. A broad range of factors is at work, but the differences between groups are clear and common. For example, the overall death rates for black males in the United States is 1,000 per 100,000, but for white males it is 600; for Hispanic males, 500; and for Asian males, 373. The rate of new cancers is 10 percent higher among blacks than among whites, while the rate of mortality from cancer is 30 percent higher; this raises questions of access to health care. Similarly, the rate of heart disease is 40 percent higher in blacks than in whites, but much of this may be related to socioeconomic factors rather than race: men 25 to 54 with incomes below \$10,000 have 2.5 times the risk of men with higher incomes. Other disparities follow no particular pattern: hepatitis A is far more common among American Indians and Native Americans than among other groups; diabetes among blacks; obesity among blacks and Hispanics. Indeed, significant disparities can be documented in almost any health problem, but in almost every case it is income and education, rather than race, that appear to exert the most influence.

Dr. Norman Anderson, Director of the NIH Office of Behavioral and Social Sciences Research, described NIH's efforts to promote research on questions such as the relationship between socioeconomic status (SES) and health. Using measures such as income, education, and occupational status, researchers are investigating a number of mechanisms through which SES affects health status: access to health care, residential environment, health-promoting (or damaging) behaviors, stress and other psychological factors, and physiological mediators. At this time, however, all of these variables taken together cannot fully account for SES-based differences in health status. NIH is determined to solve this puzzle and is organizing a trans-NIH initiative to address these questions. In addition, Dr. Varmus has also designated health disparities as one of eight areas of emphasis for all of NIH. Finally, the National Institute of Environmental Health Sciences (NIEHS) is developing a research agenda on the environmental aspects of socioeconomic disparities. Both NIH and NIEHS need input and advice from the public, and from COPR, on how to shape these research initiatives.

Dr. Otis Brawley, Director of NCI's Office of Special Populations Research, distributed statistics on the incidence and mortality rates for six different cancers among different racial and ethnic groups. In almost every case, the rates for black men and women are higher than those for their white counterparts. He nevertheless insisted that "race" is a social, not a biological, construct. Consequently, although his office focuses on research directed to a special population, or research of special relevance to a special population, all research has relevance for minorities and other special populations, such as the poor and underserved populations. NCI has a longstanding commitment to include proportionate numbers of blacks, Hispanics, and American Indians in cancer treatment trials, and the results have demonstrated that equal treatment yields equal outcomes, regardless of race. Repeated studies have shown, however, that treatment is not equal in the United States: for most cancers, blacks are less likely than whites to receive prompt, definitive treatment, and perhaps one day this unequal treatment will be recognized as a major source of the unequal burden of cancer among minorities.

Dr. Michael Gottesman, NIH Deputy Director for Intramural Research, described NIH's efforts to improve the training of researchers from the communities that are most affected by health disparities. These efforts build on the assumption that minority scientists, because of their motivation and sensitivities, are far more likely to do research on diseases that disproportionately affect minority and disadvantaged populations. One such initiative is the NIH Academy, which seeks to diversify the medical research population and improve the results of NIH's existing training programs by providing additional elements for minority fellows, including intensive recruitment and mentoring, a residential facility on the NIH campus, continuity of support, partnerships with public and private organizations, and exposure to real-world problems. In response to questions from COPR members, Dr. Gottesman added that 30 percent of NIH's undergraduate summer students are from minority populations, but this percentage falls off at the graduate and postdoctoral levels; the Academy is designed in part to keep these minority students in the research "pipeline." That is, its goal is not to influence the decision to go into biomedical research, but rather to maintain and support the enthusiasm of minority students who have chosen that path. COPR and other organizations can help NIH publicize the availability of these programs and incentives.

In the general discussion that followed, one COPR member asked how investigators decide which behavioral and socioeconomic factors to measure, and how they could tell that there weren't other factors at play. Dr. Sondik replied that several groups are looking for those additional factors, such as the presence of social hierarchies and the influence of stereotypes. But for NIH, the question is how to use this information to develop a research agenda — its role is to advertise its interest in these areas, and hope that individual investigators will come up with new measures or interventions that will expand knowledge and improve care. Indeed, the NIH budget proposal for 2000 includes several initiatives of this type, such as risk factors in cardiovascular disease among blacks in the South and the outcomes of diabetes in blacks.

VII. Future Activities and Interests for COPR

Dr. Varmus listed a number of future NIH activities and added that Anne Thomas would contact Council members as to their preference for participation:

- NIH budget retreat in June 1999;
- NIH town meetings;
- COPR Associates activities;
- Government Performance and Results Act review;

- Institute Director reviews; and
- Other special tasks of interest.

Based on COPR interest, Dr. Varmus suggested several topics that might be included in the agenda for the next meeting:

- Training and recruitment into clinical and laboratory sciences;
- Protection of patients in research;
- Follow-up on the NIH budget retreat;
- Other HHS science agencies (CDC, FDA, Health Care Financing Administration) and how they interact with NIH;
- Complementary and alternative medicine; and
- Health communications, especially broader access through the Internet.

He also asked Council members to suggest additional topics of interest for subsequent meetings. The following were suggested:

- Technology transfer and the relationship between NIH and proprietary research;
- NIH's Fogarty International Center and the technical and ethical issues of research abroad;
- Human Genome Project, genetic testing, and medical privacy;
- Economic analysis and the metrics for burden of disease; and
- Lesbian health, the subject of a recent IOM report commissioned by the NIH Office of Research on Women's Health.

VIII. Adjournment

There being no further business, the meeting was adjourned at 4:10 p.m. on Wednesday, April 21, 1999. The date of the next meeting will be announced at a later date.

Attachments:

- Council Roster (Attachment A)
- List of Public Observers (Attachment B)

Anne Thomas, Executive Secretary

These minutes will be formally considered by the Council at its next meeting, and any corrections or notations will be incorporated in the minutes of that meeting.

This page last reviewed on November 28, 2011

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