

Advocates complain that NIH isn't doing enough to address minority health issues and Congress is considering a bill to create a powerful center on health disparities; NIH is launching a high-level initiative

# NIH, Under Pressure, Boosts Minority Health Research

Death rates are one of the grimmest measures of the disadvantages faced by minorities in the United States. Study after study has shown that African Americans are more likely to die of cardiovascular disease, cancer, diabetes, asthma, complications from childbirth, and many other causes. Recent data from Hispanics, Asian Americans, and Native Americans show that people in these groups, too, are more likely than whites to die from some diseases. "This is an emergency health problem," says Beverly Coleman-Miller, a visiting scholar at the Harvard School of Public Health in Boston.

Last week, the National Institutes of Health hosted members of minority communities from across the country at a meeting to discuss NIH's efforts to address the issue. The occasion was the 10-year anniversary of NIH's Office of Research on Minority Health (ORMH), but one message came through loud and clear: Almost everyone at the meeting, from social workers to institute directors, said that NIH hasn't directed as much of its power to studying and alleviating health disparities as it should. Overcoming these gaps, says NIH acting director Ruth Kirschstein, is a scientific challenge and moral imperative: "We have a responsibility to be sure that [NIH's] knowledge benefits all of our citizens, all of our communities."

Meeting participants cited several factors that impede NIH's work on minority health care issues, from the lack of minority members on grant review boards to a perceived institutional bias against behavioral research aimed at identifying better disease prevention strategies for minorities. This situation is aggravated by the fact that, as currently constituted, ORMH can't award its own grants but can only collaborate with the various institutes. In addition, several speakers pointed out that lack of trust engendered by the infamous Tuskegee syphilis project makes some African Americans wary of participating in medical research.

But the message wasn't unremittably bleak. NIH officials described an institutes-wide review currently under way to intensify its efforts, and Health and Human Services Secretary Donna Shalala pointed out that the White House budget request in-

cludes an additional \$20 million for coordinating health disparities research at NIH. Also in the works is a controversial proposal in Congress to elevate ORMH to a full-fledged center, which would give it both greater visibility and the power to fund its own projects, although it's too soon to tell whether Congress will buy the idea.

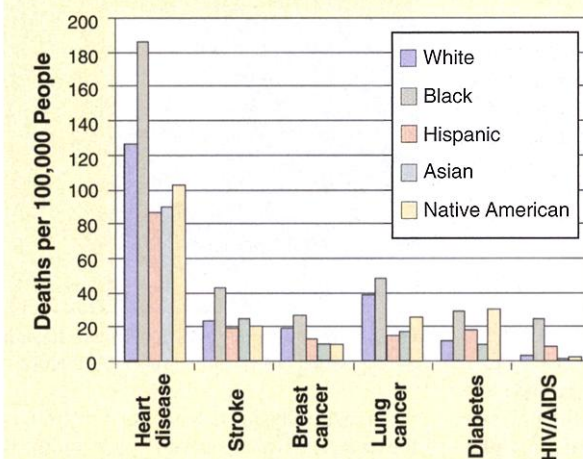
## Navigating the bureaucracy

Meeting participants cited several problems with the NIH bureaucracy—even in the ORMH. The office was established in 1990 in response to growing concern that minorities disproportionately face health problems.

men and women this year in Jackson, Mississippi, which has one of the highest incidences of stroke in the country. The goals are to assess their risk factors for heart disease and stroke and evaluate therapies and screening methods for these diseases. ORMH has also funded clinical trials on diabetes management at Charles R. Drew University, a historically black university in Los Angeles. And supplemental grants from ORMH have allowed the University of California, San Francisco, to enroll more minorities in ongoing drug-abuse studies.

The ORMH's power, however, is mainly symbolic. Its budget this year is just \$97 million—out of an NIH total of almost \$18 billion (although by some estimates, the total spent on research and training in minority health issues adds up to \$1 billion). But its biggest limitation, critics of the current system say, is that the office cannot award its own grants. ORMH serves as what ORMH director John Ruffin calls "a catalyst, a change agent." It can help identify and fund pilot projects, but it must team up with another institute that manages the research projects, even when the money comes out of ORMH's budget. Without real power, says

Age-Adjusted Death Rates for Some Common Diseases



One of the studies that raised public awareness most dramatically was a 1990 finding that men living in Harlem had a lower life expectancy than men living in Bangladesh. The NIH director charged the office with the mission to "support and promote biomedical research aimed at improving the health status of minority Americans across the life-span" and to "encourage the participation of underrepresented minorities in all aspects of biomedical and behavioral research."

ORMH has some success stories. It is the chief sponsor of the Jackson Heart Study (JHS), a longitudinal, community-based study modeled on the Framingham Heart Study. Building on an earlier study, JHS aims to enroll 6500 African-American

the American Medical Association's senior vice president for professional standards, Reed Tuckson, "the office has faced obstacles of indifference and ghettoization."

Even with ORMH's help, researchers focusing on health disparities say that navigating NIH's obstacle course of a bureaucracy can be tough. Grant applications for such research are at a disadvantage, argues Mario de la Rosa of Florida International University in Miami, because "the review process is the heart and soul of NIH, and people in the review process don't understand our communities." Angela Pattatucci Aragon of the Center for Scientific Review at NIH, which assigns review panels, adds that "there's a strong propensity to fund what has worked

SOURCE: NATIONAL CENTER FOR HEALTH STATISTICS



in the past," and that "selects against research in our communities," which have generally been poorly studied. Furthermore, some study sections fund projects that are "generalizable," which handicaps applications for research on interventions specific to one minority community.

Attitudinal biases pervade NIH, too, claims Tuckson. Studying many of the factors—such as smoking rates, access to cancer screening tests, or obesity—that have been identified as contributing to health disparities isn't considered "hard science," Tuckson says. To circumvent such problems, speaker after speaker at the ORMH conference recommended that the office be elevated within the NIH hierarchy to a center, a change that would require a congressional directive.

Representative Jesse Jackson Jr. (D-IL) and Senator Edward Kennedy (D-MA) have introduced bills into the House and Senate to do just that. Their proposal would create a National Center for Research on Domestic Health Disparities that would control its own budget, make its own grant funding decisions, and issue calls for research proposals. Support for a center was not unanimous, however. Keith Norris of Drew University says, "I worry that other institutes may feel they will no longer have to make the same effort" to study health disparities if a designated center is on the task. Former NIH director Harold Varmus also opposed such a move, pointing out that the wide range of scientific and social issues that contribute to health disparities requires the attention and expertise of all NIH institutes, not just a single center.

Even if the Jackson and Kennedy bills don't make it through Congress this year, the \$20 million discussed by Shalala should create a center within the ORMH to coordinate the health disparities research done by the institutes. It might also hold limited grant-making authority. But as Lovell Jones, director of the M. D. Anderson Cancer Center in Houston, points out, this proposal refers to a "small-c center" that would remain within the Office of the Director, rather than the "big-C Center" of the Jackson and Kennedy bills.

#### A new NIH initiative

Whether or not the ORMH metamorphoses into an independent center, NIH is hatching a systemwide plan to address health disparities. In January, a working group composed of all the institute directors—a very high-powered committee, as co-chair Yvonne Maddox, acting deputy director of NIH, points out—solicited 5-year plans from each institute. Committee co-chair Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases (NIAID), says the effort will allow NIH to "formalize and

concretize some things we've done all along," as well as initiate new research and training projects.

The working group is focusing on six primary areas: cancer screening and management, cardiovascular disease, diabetes, HIV and AIDS, infant mortality, and mental health. Other conditions, such as glaucoma, deafness, and asthma, will come in for attention as well, Maddox says. Once the working group receives all the institutes' plans—some institute directors missed the 3 April deadline—it will integrate them and forward a trans-NIH plan to the ORMH director and its advisory committee, who will submit a final plan to the NIH director. Fauci expects the plan to be integrated into the 2002 fiscal year budget.

Some of the initiatives proposed by the institutes will compensate for past oversights, Fauci says. For example, better tissue-typing methods are needed for African Americans, who disproportionately suffer from kidney disease and require kidney transplants. Possibly because the original tissue-typing banks, set up in the 1950s, were based on samples from whites, African Americans are more likely to suffer from transplant rejection. And National Institute of Mental Health deputy director Richard Nakamura says that more culturally sensitive standards are needed for diagnosing and treating mental disorders in minorities.

The plan will also try to rectify what is often a dearth of minority participants in clinical trials. In some cases, this is due to failure of the trial organizers to make enough of an effort to include them. That's relatively easy to fix, says Fauci. In AIDS research, for example, a majority of new HIV infections occurs in minority populations—but earlier research projects enrolled few minorities in clinical trials. Then NIAID included in its grant scoring process a measure of how accurately the proposed project reflects the population suffering from infection with HIV. "That turned it around in a couple of years," Fauci says.

But clinical trial organizers face another problem: the reluctance of minorities to sign

on. Shalala attributes this to many African Americans losing trust in the medical system after the Tuskegee syphilis project, which ran from 1932 to 1972. During that time, doctors at Alabama's Tuskegee Institute watched the course of syphilis in 399 black men—a disease they could have cured with a shot of penicillin once antibiotics became widely available after World War II.

An ambitious project recently announced by the National Cancer Institute (NCI) as part of its 5-year plan may help overcome this lack of trust. NCI has initiated a \$60 million program to establish a network of 17 regional cancer centers that will conduct research and run outreach and training programs in minority communities. The institutions serve, for example, the Cocopah and Paiute tribes in the southwest, rural populations in Appalachia, Latinos in Denver, and a multicultural population in Harlem.

The hope is that these centers will provide better access to preventive health care, including education about nutrition and risky behaviors, and serve as centers for research on the disproportionate cancer burden in their communities. In addition, the research goals include making community members part of the teams that design and execute research projects. "If we don't understand the culture, the interface between culture and poverty, we cannot solve the cancer problem. We need to understand the [disease] in the context of what's happening to the human being," says Harold Freeman, chair of the President's Cancer Panel. The NCI networks, he says, will help the NCI involve people "who will ask the questions that have not yet been asked or answered."

Ultimately, however, Tuckson urged participants at the ORMH conference not to focus just on bureaucratic reorganization or temporary plans: "I hope at the end of the day, it's irrelevant whether we have an office or a center." What's needed, he says, is a "national conversation" about health that includes all Americans, not just "Leave It to Beaver's family."

—LAURA HELMUTH



Ruffin



Maddox



Fauci

The NIH team. Their plan tackles minority health disparities.