

Summary of Research Activities by Disease Categories

Minority Health and Health Disparities

The Medical Committee for Civil Rights (later the Medical Committee for Human Rights) was formed in the early 1960s and participated in the 1963 March on Washington, where Dr. Martin Luther King gave his famous “I have a dream” speech. The group succeeded in highlighting racial inequalities in American medicine during a time when racial segregation in professional medical associations, hospitals, and medical education was commonplace. It was at the second National Convention of the Medical Committee for Human Rights that Dr. King made a less well-known but equally profound speech, stating, “Of all the forms of inequality, injustice in health is the most shocking and the most inhumane.”

Introduction

Despite remarkable progress in the biomedical sciences in recent years—understanding diseases and their mechanisms and enhancing the ability to prevent, diagnose, and treat disease—significant segments of the U.S. population still are more likely than others to suffer elevated morbidity and mortality and disproportionate incidence of diseases and adverse outcomes such as cancer, cardiovascular disease, diabetes, HIV/AIDS, and infant mortality. Collectively, the term *health disparity populations* refers to racial and ethnic minorities (African Americans, Hispanics, American Indians, Alaska Natives, Asian Americans, Native Hawaiians and other Pacific Islanders) and medically underserved populations, including individuals of low socioeconomic status and those living in rural areas.

Characterization of the root causes of these health disparities has been and will continue to be the focus of considerable NIH research. As results of investigations in this area have been published over the years, a broad-brush portrait has begun to emerge of the overall causal factors contributing to the creation and persistence of health disparities. It is clear at this point that these problems are often complex and multifactorial—the unfortunate end results of an interwoven and sometimes overlapping array of disparate factors, including societal, biological, behavioral, and environmental effects. For example, studies have shown that poverty and lack of education correlate with poor health and reduced life expectancy. There is well-documented evidence that discrimination based on racial, ethnic, and linguistic differences persists in the United States and has been shown to be a biological stressor as well as an ongoing barrier to access to and quality of health care. Those barriers all too often coalesce with lack of access to health care or access only to substandard health care. In addition, some racial and ethnic minority groups are genetically susceptible to certain diseases, and this places them at increased risk when such inherited biological vulnerabilities combine with adverse social and environmental factors (e.g., poor diet, chemical exposures, economic stress). These are but a few of the many interrelated factors that contribute to the existence of unacceptable health disparities in the United States, which emphasizes the need for population research.

Thus, as the U.S. population in general has become significantly healthier in recent decades, too many individuals have continued to suffer poor health, disability, and/or premature death due to factors beyond their immediate control and conditions beyond their personal choice. Overcoming health disparities is the Nation's foremost health challenge—a formidable challenge, no doubt, but one that can and will be met through gains in knowledge and the application of that knowledge in forthright, effective interventions.

In keeping with its role as the steward of medical and behavioral research for the Nation, NIH is firmly committed to reducing and ultimately eliminating health disparities in the United States. To achieve the vision of a time when all have the opportunity for long, healthy, and productive lives, NIH incorporates the goals of improved minority health and reduced health disparities in its support of biomedical and behavioral research, research training, research capacity, outreach, and research information dissemination.

Many of these activities are multidisciplinary collaborations involving several ICs, the entire NIH, or NIH working with other entities. Efforts are guided by the *NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008*, a comprehensive, continuously evolving document that sets the overarching health disparities agenda for the entire agency. The plan, approved by the National Advisory Council on Minority Health and Health Disparities but awaiting formal clearance, focuses on three major goals: (1) to conduct and support intensive research on the pathophysiological, epidemiological, and societal factors underlying health disparities; (2) to expand and enhance *research capacity* to create a culturally competent workforce; and (3) to engage in aggressive, *proactive community outreach, information dissemination, and public health education*. All NIH ICs have a minority health/health disparities strategic plan, and those plans are captured within the NIH-wide plan. NCMHD takes the lead on NIH's health disparities agenda related to those three goals.

Established in 2000 to conduct and support research, training, dissemination of information, and other programs with respect to minority health conditions and other populations with health disparities, NCMHD's mission is to promote minority health and to lead, coordinate, support, and assess NIH efforts to eradicate health disparities. For example, NCMHD supports 76 Centers of Excellence across the Nation devoted to health disparities research, training, and outreach and has supported more than 400 collaborative research projects by creating partnerships with ICs and other agencies within HHS.

Burden of Illness and Related Health Statistics

Ongoing health disparities affecting racial and ethnic minorities are well documented and are seen in a broad spectrum of diseases and adverse outcomes. The findings consistently have shown that minorities are less likely than Whites to receive needed services, including clinically necessary procedures. These disparities are sometimes associated with socioeconomic differences and tend to diminish significantly and, in a few cases, disappear altogether when socioeconomic factors are controlled. However, some racial and ethnic disparities remain even after adjustments are made for socioeconomic differences and other factors related to health care access⁹⁴.

Despite remarkable reductions in cardiovascular morbidity and mortality over the past four decades, minorities still bear a disproportionate share of the burden. Heart disease rates have been consistently higher for the African American population than for Whites. In 2004, heart disease age-adjusted death rates for African American men (342.1 per 100,000) and African American women (236.5 per 100,000) were 30 and 37 percent higher than for White men and women, respectively⁹⁵. Similarly, in the period 1999-2004, stroke affected 3.4 percent of the African American population under 75 years old, versus 1.9 percent of Whites under 75⁹⁶. Stroke mortality in that

⁹⁴ *Institute of Medicine. The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*. Washington, DC: National Academy Press, 1999.

⁹⁵ For more information, see <http://www.cdc.gov/nchs/data/hus/hus06.pdf>

⁹⁶ For more information, see <http://www.nhlbi.nih.gov/resources/docs/cht-book.htm>

age group was two to three times higher in African Americans than in Whites⁹⁷. Death certificate data from 2002 showed that mean age at stroke death was younger among African Americans, American Indians/Alaska Natives, and Asians/Pacific Islanders than among Whites and was also younger among Hispanics than non-Hispanics⁹⁸.

Cancer deaths vary by gender, race, and ethnicity, but certain racial and ethnic groups have been shown to have lower survival rates than Whites for most cancers. For example, colorectal cancer incidence and death rates are higher among African Americans than among Whites. African American men have the highest rates of prostate, lung, colon/rectum, and oropharyngeal cancers⁹⁹.

African Americans comprised approximately 13 percent of the U.S. population but accounted for 49 percent of the estimated 38,096 new HIV/AIDS diagnoses in 2005 in the 33 states with long-term, confidential name-based HIV reporting. In 2005, HIV/AIDS rates were 72.8 per 100,000 among African Americans, 28.5 among Hispanics, 10.6 among American Indians/Alaska Natives, 9.0 among Whites, and 7.6 among Asians/Pacific Islanders¹⁰⁰.

In 2004, infant mortality rates showed a persistent disparity between African Americans (13.7 deaths per 1,000 live births) and Whites (5.7 deaths per 1,000 live births)¹⁰¹. Rates of premature birth are also higher for minority groups. Data from 2003 show that the rate of premature birth was 17.6 percent among African Americans and 13.5 percent among American Indians, whereas the rate for Whites was 11.5 percent and the rate for Asians and Pacific Islanders was 10.5 percent. For African Americans, there is also a higher percentage of low-birth-weight babies. In 2003, 13.4 percent of African American babies were born at low birth weight, compared with 6.9 percent of White babies.

The prevalence of type 2 diabetes in the African American population is nearly 70 percent higher than among Whites. American Indians and Alaska Natives have a diabetes rate more than twice that of Whites. Other health disparity populations, such as Hispanics and Asians/Pacific Islanders, also suffer disproportionately from diabetes and its complications. Hispanics are twice as likely to die from diabetes as are Whites and also have higher rates of obesity and high blood pressure¹⁰².

The prevalence of asthma among non-Hispanic African Americans was approximately 30 percent higher than among non-Hispanic Whites and approximately double that of Hispanics¹⁰³.

⁹⁷ For more information, see <http://www.cdc.gov/nchs/data/hus/hus06.pdf>

⁹⁸ For more information, see <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5419a2.htm>

⁹⁹ For more information, see http://seer.cancer.gov/csr/1975_2004

¹⁰⁰ For more information, see <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/>

¹⁰¹ For more information, see http://www.cdc.gov/nchs/data/nvsr/nvsr54/nvsr54_19.pdf

¹⁰² For more information, see <http://www.cdc.gov/nchs/nhis.htm>; http://www.cdc.gov/nchs/products/elec_prods/subject/nhanes3.htm; http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2003.pdf; <http://www.cdc.gov/mmwr/preview/mmwrhtml/00055489.htm>

¹⁰³ For more information, see <http://www.niaid.nih.gov/publications/minorityhealth.pdf>

Disease burden associated with mental disorders varies across ethnic minority populations. Native American and Alaska Natives, for example, not only suffer disproportionately from depression but also experience a higher rate of suicide than other populations¹⁰⁴. Although African Americans are less likely than Whites to experience a major depressive disorder, when they do, it tends to be more severe and lasts nearly 50 percent longer¹⁰⁵. Differences also exist within minority populations. Second- or later-generation Caribbean Black, Latino, and Asian immigrants have been found to have higher rates of mental disorders than do first-generation immigrants¹⁰⁶.

Many oral and dental diseases, including early childhood caries, oral clefting, oral cancers, and some types of periodontitis are more common, more severe, and more often untreated in disadvantaged populations, such as racial and ethnic minorities, low-income families, and inner-city and rural residents¹⁰⁷.

Clearly, these and the many other disproportionate burdens of disease suffered by racial and ethnic minorities and other disadvantaged population groups in the United States reinforce the importance of addressing health disparities through research, clinical care, public health, and health policy.

NIH Funding for Minority Health and Health Disparities Research

In FYs 2006 and 2007, NIH funding for minority health and health disparities was \$2.766 billion and \$2.744 billion respectively. The table at the end of this chapter indicates some of the research areas involved in this investment (see “Estimates of Funding for Various Diseases, Conditions, and Research Areas”).

Summary of NIH Activities

NIH has made a strong commitment to reduce and ultimately eliminate health disparities in the United States. Given the multifactorial causes of health disparities, the complex array of their manifestations in vulnerable populations, and the multidisciplinary approaches required to effectively address them, it is appropriate that this commitment is embodied in a wide variety of programs and initiatives, many of which address multiple elements, including population research. Although Research, Outreach, and Research Capacity are the major categories addressed in the *NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008*, many NIH research projects span two or all three of those endeavors. This section will address each of the major categories, providing illustrative examples, along with discussion of several important exemplary programs and/or accomplishments that do not conform to a single category.

Research

Basic, Clinical, and Translational Research

One of the most important steps on the path to eradicating health disparities is to gain useful new knowledge regarding the causes, mechanisms, natural history, prevention, and treatment of diseases in which disparities have

¹⁰⁴ For more information, see <http://www.cdc.gov/ncipc/pub-res/natam.htm>

¹⁰⁵ [Joe S, et al. JAMA. 2006;296:2112-23](#), PMID: 17077376

¹⁰⁶ [Takeuchi DT, et al. Am J Public Health. 2007;97:11-12](#), PMID: 17138903

¹⁰⁷ For more information, see <http://www.nidcr.nih.gov/DataStatistics/SurgeonGeneral/sgr/execsum.htm>

been demonstrated. As the Nation's leader in biomedical research, NIH conducts and supports basic, clinical, and translational research designed to illuminate the relationship between disease and disparities and improve patient quality of life.

For example, sickle cell disease, caused by a genetic defect, afflicts mainly African Americans, 1 in 12 of whom carries the trait. NIH funds 10 [Comprehensive Sickle Cell Centers](#) (CSCCs), which focus on multidisciplinary programs of basic, applied, and clinical research and also provide relevant patient services in diagnosis, counseling, and education concerning sickle cell disease and related disorders. The CSCCs also support multicenter Phase II clinical trials, neuroimaging studies, and the development of a collaborative database of individuals from participating centers who are potentially eligible for inclusion in any sickle cell research study. Ten centers are funded through FY 2007, and the program will be renewed in FY 2008.

The [Jackson Heart Study](#), a partnership of NIH and three local academic institutions, is the largest investigation of cardiovascular disease that has been undertaken in an African American population—a cohort of more than 5,000 African Americans in the Jackson, Mississippi, area. Death rates for cardiovascular disease in the United States are considerably higher among African Americans. Cardiovascular disease death rates in Mississippi are the highest in the Nation and are particularly high among African Americans. One important component of this longitudinal study is the use of new imaging techniques to assess physiological characteristics that may yield a significant additional understanding of heart disease in this minority population.

The Centers of Research Translation program translates basic research discoveries into clinical trials for diagnostic approaches and treatments. The focus of one of the current centers is on lupus, an autoimmune disease that disproportionately affects African American women as well as women of Hispanic, Asian, and Native American descent. Investigators are examining the role of different cell types in the origin and development of lupus and developing markers of disease activity and severity with the goal of identifying new targets for treatment.

Epidemiological/Population Research

NIH fosters considerable epidemiological and population research conducted mainly to identify, quantify, and characterize health disparities among populations, to test and monitor the effectiveness of potential interventions, and to monitor the health status of minority groups.

Four large-scale epidemiological studies help to demonstrate NIH activities in this sector. The Hispanic Community Health Study, launched in 2006, is the largest long-term epidemiological study of health and disease in Latin American populations living in the United States. As many as 16,000 subjects of Hispanic origin—4,000 at each of four sites—will undergo a series of physical examinations and interviews to help identify the prevalence of and risk factors for a wide variety of diseases, disorders, and conditions. They also will be followed over time to monitor the occurrence of disease. The study will seek to determine the role of cultural adaptation and disparities in the prevalence and development of disease. It also will investigate why Hispanics are experiencing increased rates of obesity and diabetes and yet have fewer deaths from heart disease than non-Hispanics, and why asthma is more common in certain Hispanic groups.

The need to understand the sources of persistent health disparities in overall longevity, cardiovascular disease, and cerebrovascular disease has led to the development of the [Healthy Aging in Neighborhoods of Diversity across the Life Span](#) (HANDLS) study. By posing fundamental questions about differences in rates and risks for pathological conditions associated with aging, the study aims to disentangle the relationship between race, socioeconomic status, and health outcomes. HANDLS will include 4,000 subjects drawn from socioeconomically diverse African American and White adults in Baltimore, Maryland. The cohort will be followed over a 20-year period to allow longitudinal assessment of aging-related variables and their potential impact on health disparities.

The [Reasons for Geographic and Racial Differences in Stroke](#) (REGARDS) study is an observational study to explore the role of race and geographic differences on stroke risk factor prevalence and stroke incidence and mortality. Thirty thousand individuals, about 50 percent African American and 50 percent White, are participating in REGARDS, which has already yielded important new information about disparities in stroke.

NIH is collaborating on and supporting the Collaborative Psychiatric Epidemiology Surveys, large national surveys exploring the prevalence and characteristics of mental health disorders in the United States. The National Comorbidity Survey-Replication (Harvard Medical School), the National Latino and Asian American Study (Cambridge Health Alliance/Center for Multicultural Mental Health Research), and the National Survey of American Life (Program for Research on Black Americans/University of Michigan's Institute for Social Research) will each contribute important information on disparities in the incidence of psychiatric illnesses and mental health service usage and access among racial and ethnic minorities.

Outreach

Outreach encompasses many forms of activity, with information and intervention campaigns targeted to a wide variety of audiences, including patients, health care providers, public health educators and officials, policymakers, professional and patient advocacy organizations, and community-based groups. Disseminated information may be oriented toward a particular disease (e.g., diabetes, oral cancer, stroke), a particular group (e.g., African American men, Hispanics at high risk of HIV/AIDS, women of reproductive age), or both. Along with communications, outreach initiatives also include activities such as consultations, internships, and partnerships and collaborations with various public and private organizations.

For example, NIH and CDC work together in a grassroots education campaign called [Know Stroke in the Community](#), which enlists community leaders to become “Stroke Champions” to educate their neighbors about the signs and symptoms of stroke. The program focuses on reaching African Americans, Hispanics, and seniors (see also the section “Health Communication and Information Campaigns and Clearinghouses” in Chapter 3). Additionally, NIH collaborates with the National Coalition of Ethnic Minority Nurses Associations to increase awareness of NIH research opportunities for underserved investigators.

A wide variety of programs conduct interventions and education directly in communities in need. NIH's Oral Health Disparities Centers, which use innovative, low-cost approaches to address severe early childhood caries and oral cancer, are an excellent example of this approach. With the promising achievements of the five currently funded centers and the ongoing need to reverse severe disparities in oral health among some populations, NIH announced in May 2007 that it will fund a competing renewal of the initiative.

Many programs aim to increase health literacy among affected groups and/or to help disparity populations overcome existing barriers to access to health care. Cultural relevancy is an important factor in the success of these efforts to effectively communicate science-based medical and health information to minorities and underserved populations.

In some instances, the approach can be as straightforward—and as powerful—as communicating important information in another language. For example, [infoSIDA](#) is a Spanish-language version of the comprehensive AIDSinfo Web site administered by NIH. Some health disparities outreach efforts are segments of wider campaigns. Others expand upon successful campaigns by incorporating culturally relevant scenarios. For example, rather than translating its “Learn the Link” public service announcement about the link between noninjection drug abuse and

HIV, NIDA created a culturally relevant public service announcement that would resonate with Hispanic audiences and released both Spanish-language and bilingual versions for English-language stations with large Hispanic audiences. The [National Diabetes Education Program](#) (NDEP) and the [National Kidney Disease Education Program](#) (NKDEP) both tailor materials for minority groups at high risk. With diabetes rates soaring within the Hispanic population, NDEP's action plan encourages Hispanics to manage the “ABCs” of diabetes—A1C (a test that measures 120-day blood glucose levels), Blood pressure, and Cholesterol—to lower their risk for cardiovascular disease and other diabetes complications to improve their health and the health of future generations. NKDEP targets certain materials to African Americans, who are disproportionately vulnerable to kidney disease due in large measure to their elevated rates of diabetes and high blood pressure. More comprehensively, the National Network of Libraries of Medicine, with more than 5,800 full and affiliate members, is a key component of NIH'S outreach program and its efforts to reduce health disparities and improve health information literacy, particularly for underserved populations.

Enhanced access and improved care are the goals of the [Patient Navigation Research Program](#), an initiative that provides individualized attention to cancer patients, survivors, families, and caregivers, to help them access and then chart a course through the complexities of the health care system and overcome any barriers to quality care. The [Community Networks Program](#) aims to reduce and eliminate cancer health disparities among racial and ethnic minorities. Twenty-five projects across the United States and American Samoa address cancer disparities among African Americans, American Indians, Alaska Natives, Native Hawaiians and other Pacific Islanders, Asians, Hispanics, and rural underserved populations.

Research/Outreach

Many NIH activities that address minority health and health disparities incorporate a synergistic blend of research and outreach. These projects may involve one or more outreach elements such as education, awareness, recruitment of study/clinical trial subjects, and a variety of clinical and preventive interventions, often translational in nature. Frequently, programs provide information and interventions to targeted populations on a pilot basis, so that researchers can collect valuable data and feedback on how effectively the initiative is addressing the problem of interest. Many such programs incorporate community-based participatory research, in which scientific inquiry is conducted in partnership with the community of patients, caregivers, and other stakeholders who participate in the research.

[Head Off Environmental Asthma in Louisiana](#) (HEAL), funded in part by NIH, illustrates these concepts in its activities in post-Katrina New Orleans. Childhood asthma is on the rise in the United States, especially among minority inner-city children. Up to 24 percent of minority children living in cities like New Orleans may have asthma. The rapidly increasing rates of asthma are thought to be related in part to increases in allergies and environmental exposures, such as mold, moisture, and other allergens. Lack of access to health care may be another contributing factor. Those problems are especially prevalent in post-Katrina New Orleans, where HEAL conducts research on the effects of exposure to mold and other indoor allergens on children with asthma, as well as inherited differences in their responses. HEAL research will yield important biomedical knowledge about a growing public health problem while contributing to improved care for children with asthma in a challenging environment.

The Gila River Indian Community Longitudinal study of Pima Indians of Arizona, who have the highest prevalence of diabetes in the world, has made substantial progress in identifying genetic, physiologic, and behavioral factors that contribute to obesity and diabetes. The community has benefited from improved treatment and prevention services, leading to better blood glucose control and blood pressure among the Pima with diabetes.

The [Look AHEAD \(Action for Health in Diabetes\)](#) multicenter clinical trial is following 5,100 obese subjects with type 2 diabetes for 11.5 years. The study's objective is to compare the effects on cardiovascular outcomes of a long-term intensive lifestyle intervention designed to achieve and maintain weight loss, as well as a control program of diabetes education and support. The project includes considerable outreach activities to help subjects improve their health.

Low health literacy is a widespread problem, affecting more than 90 million adults in the United States, many of whom are members of disparity populations facing several other barriers to care. *Understanding and Promoting Health Literacy*, a Program Announcement by NIH and the Agency for Healthcare Research and Quality, is designed to encourage empirical research on health literacy concepts, theory, and interventions, to help accomplish the HHS *Healthy People 2010* objective of improved national health literacy by the decade's end.

Research Training

Promoting diversity in education and research is an essential component of the NIH mission to improve health through research. NIH and ICs provide several intramural and extramural programs to promote diversity in research training, increasing the breadth of representation and participation of groups that have been shown to be underrepresented, including individuals from underrepresented racial and ethnic groups, individuals with disabilities, and individuals from disadvantaged backgrounds. These programs address all career levels in the biomedical and behavioral sciences workforce and include clinical research training. The Minority Biomedical Research Support's (MBRS's) Support of Competitive Research (SCORE) Institutional Development Award program supports research projects that foster diverse faculty and student participation in biomedical research, thereby helping to create a growing and diverse cadre of scientists who are making important contributions in the health sciences. The Research Initiative for Scientific Enhancement (RISE) program develops the research potential of faculty and students. NIGMS also supports several research training programs to increase diversity in the biomedical research workforce: the Minority Access to Research Careers (MARC) Undergraduate Student Training in Academic Research (U-STAR) program, predoctoral fellowships, faculty fellowships and Visiting Scientist Fellowships, ancillary training activities, and the Post-Baccalaureate Research Education Program (PREP). The MBRS and MARC programs are institutional programs and do not use race or ethnicity as a criterion for individuals supported by the program. Many of these programs are offered by the NIGMS's Division of Minority Opportunities in Research, which maintains a [Web site](#) that provides centralized information and an [overview of programs by career stage](#). Other examples of extramural and intramural programs include the NIH Academy; the Ruth L. Kirschstein National Research Service Awards for Individual Predoctoral Fellowships to Promote Diversity in Health-Related Research, as mandated by Federal law (Section 487(a)(4) of the Public Health Service Act, as amended); the Undergraduate Scholarship Program (UGSP), as mandated by Federal law (Section 487D of PHS Act, as amended); and the Research Supplements to Promote Diversity in Health-Related Research (Diversity Supplements; PA 05-015).

Research Capacity

To accomplish its mission to reduce and ultimately eliminate health disparities in the United States, NIH believes that it is imperative to increase and enhance research capacity in this area in order to ensure that current and future needs are addressed. The ultimate goals are to support research, expand opportunities in training, foster career development, and increase research funding for health disparities research. A variety of projects address the need to recruit, retain, and provide career development opportunities for all scientists (particularly those from underrepresented backgrounds), as well as to expand the number of investigators pursuing health disparities

research. Such programs provide direct support to individuals and also fund expansion and infrastructure improvements at numerous institutions, including historically Black colleges and universities and others commonly referred to as minority-serving institutions.

Many ICs have existing programs that contribute to increased research capacity in the area of minority health and health disparities. NCMHD leads the Federal effort at NIH to stimulate new research and promote programs aimed at expanding the participation of underrepresented minorities in all aspects of biomedical and behavioral research. The [Research Infrastructure in Minority Institutions](#) (RIMI) research infrastructure grant program is designed to strengthen the research environment of predominantly minority-serving academic institutions through grant support to develop and/or expand existing capacities for institutional and/or individual faculty-initiated basic, biomedical, social, and/or behavioral research programs. Two NIH loan repayment programs seek to recruit and retain highly qualified health professionals who have doctorate degrees and are from health disparity populations and disadvantaged backgrounds to pursue health disparities or clinical research; they are [Loan Repayment Program for Minority Health Disparities Research](#) and the [Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds](#)¹⁰⁸. Today, the NIH has 71 [Health Disparities Centers of Excellence](#) across the Nation. These Centers of Excellence, now located in 26 States, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, support health disparities research, research training, and community involvement to identify factors that contribute to health disparities and to develop and implement new diagnostic, treatment, and prevention strategies (see Chapter 4).

The [Research Centers in Minority Institutions](#) (RCMI) Program began in 1985 in response to congressional report language (House Report 98-911, on the Labor, Health and Human Services, and Education and Related Agencies Appropriation Bill for FY 1985 [July 26, 1984, pages 78-79]) directing funds to “establish research centers in those predominantly minority institutions which offer doctoral degrees in the health professions or the sciences related to health.” RCMI support includes funds to recruit established and promising researchers, acquire advanced instrumentation, modify laboratories for competitive research, and to fund core research facilities and other research support. The [Institutional Development Award](#) (IDeA) program fosters health-related research and increases the competitiveness of investigators at institutions in 23 states and Puerto Rico, which have historically low aggregate success rates for grant awards from NIH. The program facilitates multidisciplinary collaborations, provides workforce development, enhances research infrastructure, and supports research to reduce health disparities in minority populations within IDeA-eligible states, such as among American Indians, Alaska Natives, Hispanics, and Native Hawaiians and other Pacific Islanders. Each of these and many similar programs throughout NIH contribute to eliminating health disparities in the United States by addressing the national need to develop a diverse, strong, and culturally competent scientific workforce, and by fostering increased research activity focused on health disparities.

Conclusion

The goal of reducing and ultimately eliminating health disparities in the United States remains one of NIH's top priorities in its efforts to improve and protect the health and well-being of all Americans. Every IC has its own strategic plan to combat health disparities in its area of influence. Agency-wide activities are guided by the comprehensive NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008, with NCMHD serving as the focal point for planning and coordinating minority health and health disparities research. NIH is also committed to broadening collaborative relationships developed through partnerships between NIH and institutions and researchers from all populations.

¹⁰⁸ Sec. 485 G of PHS Act, as amended; Sec. 487 E - F of PHS Act, as amended.

Health disparities arise due to a complex matrix of physical and cultural influences, and a robust, integrative, sustained approach is required to meet the profound challenges they represent. As has been seen in this chapter, that is precisely the approach being taken by NIH in its efforts to eradicate one of the Nation's most perplexing and intransigent public health problems.

Notable Examples of NIH Activity

Key for Bulleted Items:

E = Supported through Extramural research

I = Supported through Intramural research

O = **O**ther (e.g., policy, planning, and communication)

COE = Supported through a congressionally mandated **C**enter of **E**xcellence program

GPRA = Concerns progress tracked under the **G**overnment **P**erformance and **R**esults **A**ct

Basic, Clinical, and Translational Research

Sildenafil for Pulmonary Hypertension in Adult Patients with Sickle Cell Disease: In 2006, NIH began a new study to evaluate a course of treatment with sildenafil in patients with sickle cell disease who have pulmonary hypertension. A randomized, double-blind, placebo-controlled, Phase II clinical trial is testing the drug's safety and efficacy in improving exercise capacity, symptoms, and measures of circulatory function. The trial involves approximately 180 patients at extramural sites and at the NIH Clinical Center. Because pulmonary hypertension occurs frequently in persons with sickle cell disease and confers a high risk of death, a positive outcome of this trial would represent an important step toward improved patient care.

- For more information, see <http://www.clinicaltrials.gov/ct2/show/NCT00492531?term=sildenafil>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Clinical and Translational Research*.
- (E/I) (NHLBI)

Comprehensive Sickle Cell Centers (CSCCs): The CSCCs were established in 1972 in response to a Presidential initiative and a Congressional mandate to support multidisciplinary research to expedite development and application of new knowledge for improved diagnosis and treatment of sickle cell disease. In addition to basic research, training, and patient services activities, the CSCCs currently support multicenter Phase II trials, neurocognitive and neuroimaging studies, development of a collaborative database, and a study on the epidemiology of priapism (painful, prolonged erection) among sickle cell patients. Ten centers were funded through FY 2007, and the program was in FY 2008.

- For more information, see <http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-06-008.html>
- For more information, see <http://www.sicklecell-info.org/>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Clinical and Translational Research*
- (E) (NHLBI)

Jackson Heart Study: The Jackson Heart Study, a large epidemiological study of cardiovascular disease (CVD) among over 5,300 African American residents of Mississippi, has been renewed through FY 2013. The project is exploring genetic, biological, and environmental factors that influence the development and course of CVD in African Americans. It is also seeking to expand minority participation in public health and epidemiological research by providing classes and hands-on training to interested undergraduate students. Moreover, a community health education component is using data derived from the study cohort to develop and disseminate up-to-date information on reduction of risk factors, practice of healthy lifestyles, and adherence to proven risk-reducing therapies.

- For more information, see <http://jhs.jsums.edu/jhsinfo/>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Epidemiological and Longitudinal Studies*
- (E) (NHLBI, NCMHD)

Centers of Research Translation (CORT): NIH launched its CORT program to unite basic and clinical research in a way that translates basic discoveries into diagnostic approaches and treatments. The first set of centers, focusing on lupus, orthopaedic trauma care, scleroderma, and a genetic form of rickets (a childhood disorder characterized by a softening and weakening of bones), began in FY 2006 and are funded through FY 2011.

- For more information, see http://www.niams.nih.gov/News_and_Events/Press_Releases/2006/11_08.asp
- This example also appears in Chapter 3: *Clinical and Translational Research*.
- (E) (NIAMS)

Translational Research for the Prevention and Control of Diabetes and Obesity: NIH is supporting research projects to explore ways to bring knowledge from successful clinical research into medical practice and community settings. Studies are seeking to develop effective, sustainable, and cost-effective methods to prevent and treat type 1 and type 2 diabetes and obesity in clinical health care practice and other real-world settings. Many of these studies focus on minority populations disproportionately burdened by type 2 diabetes and obesity.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PAR-06-532.html>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Clinical and Translational Research*.
- (E) (NIDDK)

Trans-NIH Management and Coordination of HIV/AIDS Research in Racial and Ethnic Populations: In the United States, AIDS disproportionately affects racial and ethnic minority populations. NIH response to the HIV/AIDS epidemic is a unique and complex multi-institute, multidisciplinary research program. NIH supports a comprehensive program of basic, clinical, and behavioral research on HIV infection and its associated co-infections, opportunistic infections, malignancies, and other complications that are prevalent in or specific to racial and ethnic populations in the United States. This research transcends every area of clinical medicine and basic scientific investigation, crossing the boundaries of nearly every NIH IC. The Office of AIDS Research (OAR), located within the NIH Office of the Director, coordinates the scientific, budgetary, and policy elements of NIH AIDS research and has established a specific focus on the epidemic in minority communities. The Racial and Ethnic Minorities section of OAR has established the Ad Hoc Working Group on Minority Research, which includes representatives from key ICs, other HHS agencies, and non-Government experts and community representatives to assist in the development of an annual strategic plan and for collaboration and information exchange about scientific priorities and opportunities. Through its unique, trans-NIH planning, budgeting, and portfolio assessment processes, OAR ensures that research dollars are invested in the highest-priority areas of scientific opportunity, allowing NIH to

pursue a united research front against the epidemic in U.S. minority populations.

- For more information, see <http://www.oar.nih.gov>
- (O) (OAR)

Osteoarthritis: African Americans have a higher risk of both bilateral radiographic (x ray-defined) knee and hip osteoarthritis than Whites. Two NIH-funded studies have revealed that mechanical stress can increase the production and release of osteoarthritis-related biomarkers. The research highlights the importance, when analyzing biomarkers, of considering the type and degree of physical activity in which patients with osteoarthritis participate.

- [O'Kane JW, et al. *Osteoarthritis Cartilage* 2006;14:71-6, PMID: 16188465](#)
- [Piscoya JL, et al. *Osteoarthritis Cartilage* 2005;13:1092-9, PMID: 16168680](#)
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems*.
- (E) (NIAMS)

Systemic Lupus Erythematosus (Lupus): The incidence of lupus is three times higher in African American women than in White women, and it is also more common in women of Hispanic, Asian, and Native American descent. NIH-supported researchers have reported that, for most women with moderate lupus that is inactive or stable, taking estrogen—whether as oral contraception or hormone replacement therapy—appears to have no detrimental effect on disease activity. Additionally, researchers working in mice have shown that blocking the effects of two proteins, which normally recognize viruses and bacteria and activate immune cell responses against them, produced different and unexpected effects on disease severity, suggesting these proteins might be new targets for lupus treatment.

- [Petri M, et al. *N Engl J Med* 2005;353:2550-8, PMID: 16354891](#)
- [Christensen SR, et al. *Immunity* 2006;25:417-28, PMID: 16973389](#)
- For more information, see http://www.niams.nih.gov/News_and_Events/Press_Releases/2005/12_22.asp
- For more information, see http://www.niams.nih.gov/News_and_Events/Spotlight_on_Research/2007/proteins_lupus.asp
- (E) (NIAMS, NCMHD, NCRR, NIAID, ORWH)

Vitiligo: Vitiligo is a skin disease characterized by a loss of pigment in all people who are affected. The psychological and social consequences can be particularly profound in affected people of color. A study of 133 families with vitiligo found that family members, even those who do not have vitiligo, are also predisposed to other, potentially more serious autoimmune diseases.

- [Jin Y, et al. *N Engl J Med* 2007;356:1216-25, PMID: 17377159.](#)
- For more information, see http://www.niams.nih.gov/News_and_Events/Press_Releases/2007/04_10.asp
- This example also appears in Chapter 2: *Autoimmune Diseases*.
- (E) (NIAMS, NIAID, NIDDK)

Epidemiological/Population Research

Multi-Ethnic Study of Atherosclerosis (MESA): In an ancillary study to the NHLBI-sponsored MESA, retinal disease was assessed in more than 6,000 African American, Hispanic, White, and Asian subjects in this large, population-based study of cardiovascular health. The eyes of African American and Hispanic study subjects are more likely to have signs indicative of diabetic eye disease, whereas the eyes of White and Chinese subjects are more likely to show signs of age-related macular degeneration. Other analyses demonstrate racial and/or ethnic differences in

the relative size and characteristics of the blood vessels lining the back of the eye, which are associated with various cardiovascular profiles. Future analyses will expand on these results and will consider the impact of genes, alone and in combination with differential exposure to environmental factors, such as cigarette smoke and air pollution, on retinal health.

- For more information, see <http://www.mesa-nhlbi.org/default.aspx>
- This example also appears in Chapter 3: *Epidemiological and Longitudinal Studies*.
- (E/I) (NHLBI, NEI)

Value of early HIV Screening, Testing, and Counseling: HIV/AIDS disproportionately affects several minority groups, particularly African Americans. Although adult and adolescent African Americans make up approximately 13 percent of the population, they accounted for half of the new HIV/AIDS diagnoses in 2001-2005. This disparity is particularly striking because African Americans do not have higher rates of addiction or intravenous drug use than Whites. One contributing factor is that African Americans are often diagnosed with HIV infection at a later point in the illness, increasing their likelihood of progressing to AIDS and of transmitting the disease. As part of efforts to prevent late diagnosis and HIV spread, NIH is working to identify and address the cultural barriers to making HIV screening more acceptable and to strengthen the link between education, testing and counseling, and treatment within all ethnic groups. Indeed, NIH-supported modeling research has shown that routine HIV screening, even among populations with prevalence rates as low as 1 percent, is as cost-effective as screening for other conditions, such as breast cancer and high blood pressure. These findings have important public health implications, recognized by CDC, which has called for increased HIV screening as part of its recommended guidelines. NIH is eager to advance new HIV rapid-screen technologies and counseling in community drug treatment programs and in criminal justice settings.

- For more information, see <http://www.drugabuse.gov/ResearchReports/hiv/hiv.html>
- For more information, see <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm>
- This example also appears in Chapter 2: *Infectious Diseases and Biodefense* and Chapter 3: *Clinical and Translational Research*.
- (E) (NIDA)

Healthy Aging in Neighborhoods of Diversity Across the Life Span (HANDLS): HANDLS is a community-based study to evaluate health disparities in socioeconomically diverse African American and white adults in Baltimore. Recruitment to date, which has resulted in almost 2,000 subjects in the Baltimore area, will continue for 2 additional years to complete cohort recruitment of 4,000 subjects. Scientists are using mobile medical research vehicles to make possible on-site bone density and carotid artery imaging, physical examination and blood sampling, physical and cardiovascular performance, subject interviews, cognitive testing, and psychophysiological testing. HANDLS will also include studies of other variables, including: nutrition, environment and neighborhood effects, genetic make-up, family history, access to health care. Subjects will be followed over a 20-year period to allow researchers to gain insights into the physical, genetic, biologic, demographic, and psychosocial traits that may be most critical for healthy aging.

- For more information, see <http://handls.nih.gov>
- (I) (NIA)

National Epidemiologic Survey on Alcohol and Related Conditions (NESARC): This nationally representative survey collected comprehensive, detailed data from approximately 40,000 individuals on alcohol consumption, use of 10 categories of drugs, and symptoms of alcohol and specific drug use disorders, as well as mood, anxiety, and personality disorders. In addition to diagnostic criteria, NESARC assessed indicators of impairment and distress due

to each disorder, as well as disorder-specific treatment and help seeking. Analysis of these data is ongoing and continues to provide valuable information such as prevalence and comorbidity of mental health and substance use disorders. In addition, because NESARC data includes a representative sample of ethnic and racial minority populations in the United States, a better assessment of the needs of specific populations can be made. One recent study using this data examined differences in the use of alcohol treatment services across the three largest ethnic groups in America. It showed Hispanics and African Americans with higher levels of problem severity were less likely to have used treatment services than Whites with problems of comparable severity, providing useful information about disparities in treatment utilization.

- [Schmidt LA, et al. *Alcohol Clin Exp Res* 2007;31:48-56](#), PMID: 17207101
- For more information, see <http://pubs.niaaa.nih.gov/publications/arh29-2/toc29-2.htm>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems*, Chapter 2: *Life Stages, Human Development, and Rehabilitation*, and Chapter 3: *Epidemiological and Longitudinal Studies*.
- (E/I) (NIAAA)

A Look at Drug Abuse Trends: Local to International: Several major systems of data collection are helping to identify substance abuse trends locally, nationally, and internationally: Monitoring the Future Survey (MTF), the Community Epidemiology Work Group (CEWG), and the Border Epidemiology Work Group (BEWG). All help to surface emerging drug abuse trends among adolescents and other populations and guide responsive national and global prevention efforts. The MTF project, begun in 1975, has many purposes, the primary one being to track trends in substance use, attitudes, and beliefs among adolescents and young adults. The survey findings are also used by the president's Office of National Drug Control Policy to monitor progress toward national health goals. The MTF project includes both cross-sectional and longitudinal formats—the former given annually to 8th, 10th, and 12th graders to see how answers change over time, and the latter given biennially, or every 2 years (until age 30, then every 5 years) to follow up on a randomly selected sample from each senior class. CEWG, established in 1976, provides both national and international information about drug abuse trends through a network of researchers from different geographic areas. Regular meetings feature presentations on selected topics, as well as those offering international perspectives on drug abuse patterns and trends. A recently established Border Epidemiology Work Group represents a collaboration of researchers from both sides of the U.S.-Mexico border. Of special interest are drug abuse patterns and problems in geographically proximal sister cities/areas. Development of a Latin American Epidemiology Network is under way. NIH has also provided technical consultation for the planning and establishment of an Asian multicity epidemiological network on drug abuse.

- For more information, see <http://www.monitoringthefuture.org>
- For more information, see <http://www.drugabuse.gov/about/organization/CEWG/CEWGHome.html>
- This example also appears in Chapter 3: *Disease Registries, Databases, and Biomedical Information Systems* and Chapter 3: *Epidemiological and Longitudinal Studies*.
- (E) (NIDA)

HEALTHY: The HEALTHY multicenter clinical trial aims to prevent risk factors for type 2 diabetes in middle-school children. A pilot study for HEALTHY found that an alarmingly high 15 percent of students in middle schools enrolling mainly minority youth had three major risk factors for diabetes; about half of the children were overweight. These data suggest that middle schools are appropriate targets for efforts to decrease risks for obesity and diabetes. In the full-scale HEALTHY trial, 42 enrolled middle schools receive the intervention, which includes changes to school food service and physical education classes, behavior change, and communications campaigns. More than 80 percent of the enrolled students are from minority populations.

- For more information, see <http://www.nih.gov/news/pr/aug2006/niddk-28.htm>

- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 2: *Life Stages, Human Development, and Rehabilitation*.
- (E) (NIDDK)

Head Off Environmental Asthma in Louisiana: Nearly 20 million people, 6.5 million of them children, suffer from asthma in the United States, and minorities are disproportionately represented. NIH and others, co-fund the Head Off Environmental Asthma in Louisiana (HEAL) project to assess the impact on asthma of environmental health conditions that were caused and exacerbated by Hurricane Katrina in New Orleans children, as well as implement an intervention program to address these problems. The Project's three main goals are (1) to conduct an extensive epidemiology study to assess the nature of the environmental and psychological impacts on children in New Orleans of Hurricane Katrina and subsequent flooding; (2) to examine the genetic and environmental risk factors for asthma, including genetic susceptibility to mold toxins, and gene interactions; and (3) to design, implement, and evaluate a case management program to meet the health care needs of children with asthma in a disrupted and highly challenging environment. The project has a clear plan for informing the community of the goals, implementation, and outcome, as well as for receiving input from the community.

- For more information, see <http://heal.niehs.nih.gov/>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Clinical and Translational Research*.
- (I) (NIEHS, NCMHD)

NIH Collaborative Psychiatric Epidemiology Surveys (CPES): Through cooperative agreements, NIH supports the National Comorbidity Survey Replication (NCS-R), the National Latino and Asian American Study (NLAAS), and the National Survey of American Life (NSAL). These studies are large, nationally representative surveys assessing the prevalence and correlates of mental health disorders. The NLAAS provides national information on the similarities and differences in mental illness and service use of Latinos and Asian Americans. The objectives of the NSAL are to investigate the nature, severity, and impairment of mental disorders among national samples of the African American and non-Hispanic White populations in the United States.

- For more information, see <http://www.hcp.med.harvard.edu/ncs>
- For more information, see <http://www.multiculturalmentalhealth.org/nlaas.asp>
- For more information, see <http://www.rcgd.isr.umich.edu/prba/nsal.htm>
- This example also appears in Chapter 3: *Epidemiological and Longitudinal Studies*.
- (E) (NIMH)

Hispanic Community Health Study: In October 2006, NIH began the largest long-term epidemiological study of health and disease ever conducted in people of Latin American heritage living in the United States. The project, which will include about 16,000 subjects, is designed to identify factors that predispose individuals to develop heart disease, stroke, asthma, COPD, sleep disorders, dental disease, hearing loss, diabetes, kidney disease, liver disease, cognitive impairment, and other chronic conditions. Characteristics such as diet, physical activity, obesity, smoking, blood pressure, blood lipids, acculturation, socioeconomic status, psychosocial factors, occupation, health care access, environment, and use of medications and dietary supplements will be assessed.

- For more information, see <http://www.nhlbi.nih.gov/new/press/06-10-12.htm>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Epidemiological and Longitudinal Studies*.
- (E) (NHLBI, NCMHD, NIDCD, NIDCR, NIDDK, NINDS, ODS)

Jackson Heart Study Advanced Imaging Component: The Jackson Heart Study is a longitudinal study of heart

disease and cardiovascular disease in about 5,000 African Americans in the Jackson, Mississippi area. Data collection for this study began in 2000. New imaging techniques that include dynamic MRI of the heart to assess cardiac function and computed tomography (CT) imaging to assess visceral abdominal fat and calcification of the aorta and coronary vessels. These imaging data can provide significant additional understanding of heart disease in this minority population. NIH is in the process of adding these valuable components to the study of heart disease. The CT studies began in spring of 2007, and the MRI studies will begin in early 2008.

- For more information, see <http://www.nhlbi.nih.gov/about/jackson/index.htm>
- (E) (NIBIB, NCMHD, NHLBI)

U.S.-Born Children of Immigrants May Have Higher Risk for Mental Disorders Than Parents: In the first studies to examine the effects of immigration and years of residence on the mental health of Caribbean Black, Latino, and Asian populations in the United States, NIH-funded researchers found that immigrants in general appear to have lower rates of mental disorders than their U.S.-born counterparts.

- For more information, see http://www.nimh.nih.gov/press/immigrant_mentalhealth.cfm
- This example also appears in Chapter 3: *Epidemiological and Longitudinal Studies*.
- (E) (NIMH)

Retinopathy Occurs in Middle-Aged Adults Even Without Diabetes: Signs of retinopathy are common in the eyes of the elderly, particularly in those with diabetes. In the Atherosclerosis Risk in Communities (ARIC) Study, African American subjects were significantly more likely to have signs of retinopathy (13 percent) than were White subjects (5.5 percent). Among people with diabetes, 27 percent had signs of retinopathy. Unexpectedly, retinopathy signs were also observed in 4.3 percent of people who did not have frank diabetes but tended to have elevated blood pressure. Future studies will examine whether these signs of retinopathy result from high blood pressure and whether they indicate an increased risk of systemic cardiovascular disease or predict a subsequent diagnosis of diabetes.

- [Wong TY et al. Am J Ophthalmol 2007;143:970-6](#), PMID: 17399675
- For more information, see <http://www.csc.unc.edu/aric>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Epidemiological and Longitudinal Studies*.
- (E/I) (NHLBI, NEI)

Outreach

Disseminating Evidence-based Health Information on Diabetes and Digestive and Kidney Diseases: The National Diabetes Education Program (NDEP) and the National Kidney Disease Education Program (NKDEP) were created to disseminate evidence-based educational material on diabetes and kidney disease, respectively. For example, the NDEP encourages people to take “small steps” to prevent type 2 diabetes. NKDEP encourages African American families to discuss kidney disease at family reunions. Both Programs tailor materials for minority groups at high risk. Information Clearinghouses also provide key health information for the public. Recent campaigns raised awareness of celiac disease and interstitial cystitis. The Weight-Control Information Network provides science-based information on topics such as obesity and nutrition.

- For more information, see <http://www2.niddk.nih.gov/HealthEducation/>
- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*

- (E) (NIDDK, CDC)

National Network of Libraries of Medicine: With more than 5,800 full and affiliate members, the National Network of Libraries of Medicine is the core component of the National Library of Medicine's outreach program and its efforts to reduce health disparities and to improve health information literacy. The Network also seeks to build and improve collaborations with community-based organizations as an effective means of reaching these populations. A major new initiative is the development of a nationwide emergency plan to ensure backup health library services in the aftermath of a disaster and to establish librarians as key community resources in disaster planning and response. In 2006, new 5-year contracts were signed for eight Regional Medical Libraries in the Network.

- For more information, see www.nlm.gov
- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (I) (NLM)

Patient Navigation Research Program (PNRP): PNRP is an intervention that addresses barriers to quality standard care by providing individualized assistance to cancer patients and survivors and their families. The program's aim is to decrease the time between a cancer-related abnormal finding, definitive diagnosis, and delivery of quality standard cancer care. PNRP will focus on the four cancers with the greatest disparity in screening and follow-up care: breast, cervical, prostate, and colorectal. Nine PNRPs reach African Americans, American Indians, Asians, Hispanics/Latinos, and rural underserved populations.

- For more information, see <http://crchd.cancer.gov/pnp/pnpr-index.html>
- This example also appears in Chapter 2: *Cancer*.
- (E) (NCI)

SIDS Outreach in Minority Communities: Since 1994, when NIH launched its campaign to reduce the risks of sudden infant death syndrome (SIDS), rates have declined more than 50 percent. Yet the disparities in the SIDS rates that existed 13 years ago continue. Today African American infants are twice as likely to die from SIDS as White infants. To help eliminate this disparity, NIH collaborated with national African American women's organizations whose members are conducting community and neighborhood workshops to highlight important yet easy steps to help reduce the risk of SIDS. In Mississippi, where the infant mortality and SIDS rates are among the highest in the country, small stipends from NIH help community organizations conduct SIDS risk reduction workshops in rural parts of the state.

- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (E) (NICHD)

Reducing Disparities in Stroke: NIH is actively engaged in a number of research projects designed to identify risk factors for stroke in minority populations and enhance prevention and treatment in these groups. The **REasons for Geographic and Racial Differences in Stroke (REGARDS)** Study is an observational study to explore the role of race and geographic differences on the prevalence of stroke risk factors and on stroke incidence and mortality. To date, researchers have recruited approximately 27,000 of a projected 30,000 individuals (about 50 percent African American and 50 percent White) and have already published a number of important findings on their baseline data. NIH has also established an acute stroke research and care center at the Washington Hospital Center, a community hospital in Washington, DC, where more than 75 percent of stroke patients are African American or Hispanic. The Center will collect data to aid in stroke prevention programs and will run two clinical trials, one on secondary stroke prevention and another on increasing the use of tissue plasminogen activator among minorities.

The program directly addresses GPRA Goal SRO-8.9.2: “By 2018, identify culturally appropriate, effective stroke prevention/intervention programs in minority communities.”

- For more information, see <http://www.regardsstudy.org/index.htm>
- This example also appears in Chapter 2: *Neuroscience and Disorders of the Nervous System*.
- (E/I) (NINDS)

Promoting Early Detection of Oral Cancer in African American Men: NIH is developing a new series of oral cancer education materials specifically for African American men, who have the highest risk of oral cancer and the lowest 5-year survival rate (only 35.6 percent) of any population in the United States. This is the first national-level effort of its kind. The first piece in the series, “Are You at Risk for Oral Cancer? What African American Men Need to Know,” is now being pretested in Washington, DC; Chicago; Los Angeles; and Columbia, South Carolina. The brochure—along with other complimentary education tools, such as fact sheets, posters, and both print and audio public service announcements—will be distributed to African American community groups around the country.

- This example also appears in Chapter 2: *Cancer* and Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (E/I) (NIDCR, NCI)

Science Education Partnership Award (SEPA) Program: SEPA increases the public's understanding of medical research by (1) increasing the pipeline of future scientists and clinicians, especially from minority, underserved, and rural kindergarten to grade 12 (K-12) students and (2) engaging and educating the general public on the health-related advances made possible by NIH-funded research. By creating relationships among educators, museum curators, and medical researchers, SEPA encourages the development of hands-on, inquiry-based curricula that inform subjects about timely issues, including obesity, diabetes, stem cells, and emerging infectious diseases. Additionally, SEPA projects are designed to enhance public trust by focusing on topics such as the clinical trials process, patient safeguards, and medical research ethics. Through SEPA exhibits at science centers and museums, the program provides educational and community outreach activities to tens of thousands of people every year. Moreover, SEPA is helping to bridge the educational gap and provide the next step in research and clinical pipelines for K-12 students interested in pursuing a career in biomedical science and providing professional development opportunities for teachers. Culturally appropriate projects have been developed to enhance the participation of African American, Hispanic, Alaska Native, American Indian, and Native Hawaiian communities. In FY 2007, SEPA supported 70 projects, of which 50 targeted middle- and high-school students and 20 were based in science centers and museums.

- For more information, see <http://www.ncrrsepa.org/>
- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (E) (NCRR)

Cancer.gov in Español: This Spanish-language version of the NCI Web site is designed to reach the Hispanic-Latino population—the fastest-growing online audience in the country—to communicate the message that cancer can be prevented and treated and to offer information on all aspects of the disease. The site is specifically tailored for Hispanics and Latinos, and pages are organized around issues of greatest concern. The site will be updated with evidence-based approaches and emerging technologies to ensure that accurate, relevant, and audience-appropriate information is provided. The site demonstrates the commitment to reducing cancer health disparities by making information readily available to underserved populations.

- For more information, see <http://www.cancer.gov/espanol>

- This example also appears in Chapter 2: *Cancer* and Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (E) (NCI)

Research/Outreach

Community-Based Participatory Research (CBPR) Program: NIH supports the development, implementation, and evaluation of intervention research by using community-based participatory research (CBPR) principles and methods in targeting diseases of major public health importance in health disparity communities. This unique multiyear CBPR initiative promotes participatory research collaborations between scientific researchers and their community partners and will engage communities in all stages of the research process for a total of 11 years. This initiative began in FY 2005 with the award of 25 3-year research planning grants. The participatory partnerships formed between researchers and the community are expected to (1) transform the research questions from researcher to community centered; (2) focus the research area, strategies, and methods to address those diseases and conditions of highest community interest and need; and (3) accelerate the identification and testing of interventions that are likely to make the largest difference in the health of the community. This phase will be followed by a competition for 5-year intervention research grants to be awarded in FY 2008 and will conclude with a 3-year research dissemination grant to be awarded in FY 2013. The current CBPR planning grantees are conducting needs assessments, focus groups, and pilot intervention studies for addressing health disparities in diabetes, cancer, cardiovascular diseases, HIV, depression, dental caries, and other diseases and conditions among health disparity populations in 20 states. In May 2007, RFA MD-07-003, “NCMHD Community-Based Participatory Research (CBPR) Initiative in Reducing and Eliminating Health Disparities,” was issued for the 5-year intervention research phase. Awards for this phase will be made in FY 2008. Current CBPR pilot intervention research studies include:

- Obesity prevention using individual, family, and community-level interventions among Native Hawaiian and Pacific Islanders in Hawaii
 - Diabetes prevention among Hispanic communities in border areas in Texas
 - Dental caries prevention among American Indian children in North and South Dakota, Nebraska, and Iowa
 - Cancer prevention among African Americans in Denver, Colorado by working with churches and faith-based organizations
 - Hypertension prevention among Filipino Americans in New York City and New Jersey
 - HIV/AIDS prevention among African Americans in North Carolina
- For more information, see <http://grants.nih.gov/grants/guide/rfa-files/rfa-md-07-003.html>
 - (E) (NCMHD)

Centers of Excellence Program: The congressionally mandated NCMHD Centers of Excellence Program¹⁰⁹ leads the effort in supporting biomedical and behavioral research in minority health and health disparities research. Launched in 2002, this program has created new partnerships that enable institutions at all levels of research capability to initiate new research programs or build new institutional and community capacity for improving minority health, eliminating health disparities, providing research training, and engaging health disparity communities in efforts to improve their health. The Centers of Excellence Program has supported 88 centers since its inception and has created hundreds of unique partnerships focused on health disparities with hospitals; tribal groups; health plans; health centers; community and faith-based organizations; civic and nonprofit health

¹⁰⁹ Pub. L. No. 106-525, Section 485F

organizations; and local, city, and State Governments. Of the 88 centers, 31 Exploratory Centers and 26 Comprehensive Centers are currently active. The research conducted by NCMHD Centers of Excellence and its community partners is contributing to both the scientific and lay knowledge base through numerous publications in the peer-reviewed scientific literature; press releases; television spots; other media, including Web sites and local and regional newsletters; and training of community members as lay health advisors. The NCMHD Centers of Excellence and associated grants are located in 31 States, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. In FY 2007, new or continuing awards establishing NCMHD Centers of Excellence were made to 40 institutions. Examples of NCMHD Centers of Excellence program projects include:

- Perceived Discrimination in Healthcare Among American Indians/Alaska Natives
- Religious Outlook on Organ and Tissue Sharing: Inflammation and Asthma
- Impact of Coronary Heart Disease Risk Perception on Health Behaviors
- Physical Activity Assessment in Multi-Ethnic Women

- (E) (NCMHD)

Research Partnerships: Fostering partnerships is a key component of the multifaceted NIH strategic approach to eliminating health disparities. The NCMHD funds a broad range of collaborations with the other NIH ICs, HHS, and other Federal agencies. Through these co-funded projects, the NCMHD magnifies its reach by leveraging the existing strengths, resources, and research potential of its key Federal research partners through an extensive array of research and training initiatives. Since its creation in 2001, NCMHD has provided more than \$300 million to support several hundred research, training, community outreach, and capacity-building projects. The NCMHD will continue to build and support viable partnerships with emphasis on engaging faith-based and community-based organizations in research and outreach. Examples of research partnerships include:

- *Jackson Heart Study* (with NHLBI), a longitudinal epidemiological study of African Americans, examines genetic, biological, and environmental risk factors for the development and progression of cardiovascular disease.
- *Sister Study* (with NIEHS) is a national study that investigates environmental and genetic breast cancer risk factors in living or deceased sisters with breast cancer.
- *Hispanic Community Health Study* (with NHLBI and others) is the largest epidemiological study of health and disease in U.S. Hispanic populations.
- *Health Disparities Bench-to-Bedside Program* (with the NIH Clinical Center) fosters collaborations between basic and clinical investigators and enhanced recruitment and retention of racial and ethnic minorities in NIH clinical research.
- *Bridges to the Future Program* (with NIGMS) promotes partnerships leading to improvement in the pool of underrepresented students being trained as the next generation of scientists.
- *Tribal Epidemiology Centers Program* (with the Indian Health Service) provides epidemiological analysis, interpretation, and dissemination of information and the development and implementation of disease control and prevention programs aimed at eliminating health disparities experienced by American Indians and Alaska Natives.
- *Racial and Ethnic Approaches to Community Health* (REACH 2010) (with CDC) is a national program for limited large-scale population surveys and surveillance systems to monitor the health status of minority populations.

- (E) (NCMHD)

Look AHEAD (Action for Health in Diabetes): This multi-center NIH-led clinical trial is examining the health effects

of an intensive lifestyle intervention designed to achieve and maintain weight loss over the long term, through decreased caloric intake and increased physical activity. The impact of the intervention on the incidence of major cardiovascular events will be evaluated in 5,100 overweight or obese subjects with type 2 diabetes. Look AHEAD is one of four trials that collectively address GPRA Goal SRO-6.2.

- The Look AHEAD Research Group. *Diabetes Care* 2007;30:1374-83, PMID: 17363746
- For more information, see <http://tinyurl.com/2xaypk>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Clinical and Translational Research*
- (E/I) (NIDDK, CDC, NCMHD, NHLBI, NINR, ORWH) (GPRA Goal)

Community Networks Program (CNP): This program aims to reduce and eliminate cancer disparities among racial minorities through community-based research, education, and training. The goals of the program are to significantly improve access to and the utilization of beneficial cancer interventions in communities with cancer disparities. A total of 25 projects across the United States and in American Samoa were launched in May 2005 to address cancer disparities among African Americans, American Indians/Alaska Natives, Hawaiian Natives and other Pacific Islanders, Asians, Hispanics/Latinos, and rural underserved populations. Ten grantees work in local areas, 10 in regional areas, and 5 in national programs. Visit: <http://crchd.cancer.gov/cnp/overview.html>.

- This example also appears in Chapter 2: *Cancer*.
- (E) (NCI)

Collaborative Community-Based Research: NIH is focusing on strategies and best practices for conducting collaborative community-based clinical and translational research, particularly in minority communities and other medically underserved communities where health disparities persist. The Institutional Development Award (IDeA) and Research Centers in Minority Institutions (RCMI) programs are encouraging efforts to build and strengthen partnerships among Government agencies and academic and private-sector organizations that are also working to improve community health outcomes. Translational, community-based research funded in several IDeA states and RCMI-supported Centers, in both urban and rural settings, is focusing on:

- Enhancing recruitment and retention of research subjects through community buy-in
- Implementing practical and effective research protocols in community health care settings
- Developing versatile and sustainable core research infrastructure to encourage community participation and leverage existing resources

In addition, in FY 2007 NIH conducted two workshops to gather specific recommendations from the community that will help shape future initiatives to enhance clinical and translational research in minority and other medically underserved communities (www.esi-bethesda.com/ncrrworkshops/Fostering/index.aspx). Workshop subjects included other HHS-agencies, such as AHRQ, CDC, the Indian Health Service, and HRSA.

- For more information, see www.ncrr.nih.gov/research_infrastructure
- This example also appears in Chapter 3: *Clinical and Translational Research*.
- (E) (NCRR)

Health Partnership Program and Community Health Center: The Health Partnership Program (HPP) is a community-based, collaborative research program between NIH and Washington, DC, area representatives. Through research with underrepresented patients affected by arthritis and other rheumatic diseases, the HPP studies health disparities and their causes and provides direction for improving the health status and outcomes of

affected minority communities. Its Community Health Center (CHC) is the platform for HPP's research, education, and training activities. The Washington, DC, Center provides the community with access to specialized care and health information and NIH researchers with access to patients most affected by rheumatic diseases. Recently, NIH published "Exploring Perceptions About the Ethics of Clinical Research in an Urban Community."

- [Grady C et al. *Am J Public Health* 2006;96:1996-2001](#), PMID: 17018826
- For more information, see http://www.niams.nih.gov/About_Us/Mission_and_Purpose/Community_Outreach/Health_Partnership/default.asp
- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (I) (NIAMS)

Oral Health Disparities Centers Initiative: In May 2007, NIH announced plans to fund a competing renewal of the Oral Health Disparities Centers Initiative due to the promising achievements of currently funded centers and the magnitude of the need for scientific advancement to eliminate disparities. Despite the remarkable improvement in the Nation's oral health over the years, not all Americans have benefited equally. Oral, dental, and craniofacial conditions remain among the most common health problems for low-income, disadvantaged, and institutionalized Americans. Unfortunately, there is no easy, one-size-fits-all solution. Much remains to be learned about the complex array of cultural, economic, genetic, and other contributory factors to these disparities and how best to overcome them. The five currently supported Centers have devised innovative, low-cost approaches to address severe early childhood caries, oral cancer, poor diet, and malocclusion.

- For more information, see <http://grants1.nih.gov/grants/guide/rfa-files/RFA-DE-08-008.html>
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (NIDCR)

The Gila River Indian Community Longitudinal Study: The NIH's Phoenix Epidemiology and Clinical Research Branch studies type 2 diabetes as it occurs among Pima Indians of Arizona, who have the highest prevalence of diabetes in the world. Working closely with Pima volunteers, the Branch has made substantial progress in identifying genetic, physiologic, and behavioral factors that lead to obesity and diabetes. The Branch also has facilitated improved treatment and prevention services in this community, leading to improved blood glucose control and blood pressure in Pima with diabetes. One important result is that the rate of kidney failure due to diabetes in Pima 45 years of age and older has declined since 1990.

- For more information, see http://intramural.niddk.nih.gov/research/labbranch.asp?Org_ID=503
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Epidemiological and Longitudinal Studies*.
- (I) (NIDDK)

Rural and Frontier Mental Health: In 2006 and 2007, NIH held several technical assistance workshops in frontier communities, such as Anchorage, Alaska, in order to improve the competitiveness of research grant applications submitted by rural mental health researchers. NIH also convened workshops in Mississippi to enable community mental health workers to cope with the aftereffects of hurricanes.

- (E) (NIMH)

Know Stroke in the Community Educational Campaign: In 2004, NIH entered a first-time partnership with the Centers for Disease Control and Prevention (CDC) to launch a new grassroots education program called Know Stroke in the Community. The program was designed to identify and enlist the aid of community leaders called

“Stroke Champions” who worked to educate communities about the signs and symptoms of stroke. The program focuses on reaching African Americans, Hispanics and seniors in communities that have the health care systems in place to treat stroke. In 2005-2006, the program had been implemented in 11 cities, educating 168 Stroke Champions who have conducted more than 600 community events.

- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses* and Chapter 2: *Neuroscience and Disorders of the Nervous System*
- (E/I) (NINDS)

InfoSIDA: NIH introduced *infoSIDA*, a Spanish-language version of the *AIDSinfo* Web site, an HHS-established site that offers the latest federally approved information on HIV/AIDS clinical research, treatment and prevention, and medical practice guidelines. *InfoSIDA* features a customized home page and a search engine that locates Spanish-language resources within *AIDSinfo*. The steering group spans NIH (OAR, NIAID, and NLM), FDA, HRSA, the Center for Medicare and Medicaid Services, and CDC.

- For more information, see <http://aidsinfo.nih.gov/infoSIDA>
- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (I) (NLM)

Minority Health: NIH works in a number of ways to share health information and develop the capacity of minority-serving educational institutions to access and use health information. NLM-sponsored programs focused on historically Black colleges and universities, the National Medical Association and their more than 25,000 physicians and associated patients of African descent, health information networks for refugees, special Web sites with health information for specific populations (Asian Americans, American Indians, peoples of the Arctic), and information fellowships for representatives from American Indian tribes, Native Alaskan villages, and the Native Hawaiian community.

- [Dutcher G, et al, J Med Libr Assoc 2007;95:330-6](#), PMID: 17641769
- For more information, see <http://sis.nlm.nih.gov/outreach.html>
- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (I) (NLM)

Community-Based Participatory Research (CBPR): CBPR is scientific inquiry conducted in communities and in partnership with researchers. Persons affected by the health condition or issue under study, or other key stakeholders in the community's health, fully participate in each phase of the work. This input offers CBPR the potential to generate better-informed hypotheses, develop more effective interventions, and enhance the translation of research results into practice. The Program Announcement “Community Participation in Research” supports CBPR on health promotion, disease prevention, and health disparities. CBPR is also the theme of the annual NIH Research on Social Work Interventions and Health Summer Institute (July 2007).

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PAR-07-283.html>
- For more information, see <http://obsr.od.nih.gov/summerinstitute2007/index.html>
- This example also appears in Chapter 3: *Clinical and Translational Research*.
- (E) (OBSSR, AHRQ, NCI, NHLBI, NIA, NIAAA, NICHD, NIDA, NIDCD, NIDCR, NIEHS, NIMH, NINR, NIOSH)

Effect of Racial and Ethnic Discrimination/Bias on Health Care Delivery: A recent report from the Institute of Medicine on unequal treatment, as well as several other recent reviews, show that racial/ethnic minorities less frequently receive appropriate care, which has an adverse impact on their health outcomes, including higher

recurrence rates, morbidity, and mortality. This Program Announcement supports research directed at developing methodology and defining the specific ways in which institutional or personal bias influence the health status, health outcomes, and utilization of health services among racial/ethnic minority patients. The Funding Opportunity Announcement also supports the development of interventions designed to reduce racial/ethnic bias or perceptions of racial/ethnic bias in the health care setting.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-07-206.html>
- (E) (OBSSR, NCI, NHLBI, NIBIB, NIDA, NIDDK)

Understanding and Promoting Health Literacy: The HHS Healthy People 2010 initiative established a national health objective to improve health literacy by the decade's end. Although many diseases and conditions can be prevented or controlled, too often people with the greatest health burdens have few fact-finding skills, the least access to health information, and least effective communication with health care providers. This Program Announcement supports research that increases our understanding of the health literacy problem and its relationship to health disparities, as well as the development of interventions to overcome the adverse consequences of low health literacy.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-07-020.html>
- This example also appears in Chapter 3: *Clinical and Translational Research* and Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*.
- (E) (OBSSR, AHRQ, NCI, NHLBI, NIA, NIBIB, NICHD, NIDCD, NIDCR, NIEHS, NIMH, NINR, NLM)

Understanding and Reducing Health Disparities: Behavioral and Social Sciences Research Contributions: This October 2006 conference highlighted three broad areas of action influencing health disparities: policy, prevention, and health care. These themes are the focus of "Behavioral and Social Science Research on Understanding and Reducing Health Disparities." These Program Announcements invite applications for basic research on the behavioral, social, and biomedical pathways giving rise to disparities in health as well as applied research on the development, testing, and delivery of interventions to reduce disparities in these three action areas. They encourage a multilevel, analytic framework (i.e., ranging from individuals to societies) and systems analytic approaches. They include research relevant to a wide range of population groups (e.g., variation by socioeconomic status, race/ethnicity, and rural-urban locality) residing in the United States. Consideration is given to multiple public health issues and their interactions (e.g., multiple morbidities rather than single illnesses) and to risk factors or causal processes common to various health conditions (e.g., smoking, diet, exercise, access to health care).

- For more information, see <http://obsr.od.nih.gov/HealthDisparities/index.html>
- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-07-379.html>
- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-07-380.html>
- (E) (OBSSR, CDC, NCCAM, NCI, NCMHD, NEI, NIA, NIAAA, NIAMS, NICHD, NIDA, NIDCD, NIDCR, NIEHS, NIMH, NINDS, NINR, NLM)

Minority Participation in Clinical Trials: NIH researchers recently reported several trust-enhancing strategies identified through a process of community engagement that may help scientists successfully recruit clinical research subjects in medically underserved populations. Open communication, ensuring confidentiality, and being attentive to the patient's rights before, during, and after the clinical trial are key.

- [Grady C et al. *Am J Public Health* 2006;96:1996-2001](#), PMID: 17018826
- For more information, see http://www.niams.nih.gov/News_and_Events/Spotlight_on_Research/2006/trial_participation.asp

- (O) (NIAMS, CC)

Culturally Sensitive Educational Program Promotes HIV Prevention Among Latino Adolescents: In the first randomized, controlled trial of a culturally tailored HIV risk reduction program for Hispanic adolescents, NIH-supported investigators reported long-term success in reducing risk behaviors. HIV and AIDS disproportionately affect Hispanic adolescents; the incidence of AIDS for adult and adolescent Hispanics in 2001 is more than three times higher than among their non-Hispanic White counterparts. Subjects in the study were randomly assigned to one of two interventions: a general health promotion program or the HIV education/prevention program called “¡Cuidate!” (“Take Care of Yourself”). Both programs presented Hispanic cultural values as an important context that supports positive health behaviors. The study found that the adolescents who received the HIV prevention program reported a lower frequency of sexual intercourse, fewer sexual partners, and an increased use of condoms during intercourse for up to 12 months after completing the program. Results also suggested that it is beneficial to provide education on both abstinence and safe sex practices.

- [Villarruel AM, et al. Arch Pediatr Adolesc Med 2006;160:772-7](#), PMID: 16894074
- For more information, see <http://www.nih.gov/news/pr/aug2006/ninr-07.htm>
- (E) (NINR)

Research Training

Minority Biomedical Research Support/Research Initiative for Scientific Enhancement MBRS/RISE:¹¹⁰ MBRS was created in response to a legislative mandate to “increase the numbers of underrepresented minority faculty, investigators and students engaged in biomedical and behavioral research, and to broaden the opportunities for underrepresented minority faculty and students for participation in biomedical and behavioral research.” Hence, the objective of the MBRS program is to support research projects that foster diverse faculty and student participation in biomedical research, thereby helping to create a growing and diverse cadre of scientists who are making important contributions in the health sciences. To accomplish these goals, RISE provides support for faculty and student development activities, which can include on- or off-campus workshops, specialty courses, travel to scientific meetings, and research experiences at on- or off-campus laboratories. Support is also available for evaluation activities. RISE also offers some support for institutional development, which includes limited funds for the renovation or remodeling of existing facilities to provide space for an investigator to carry out developmental activities, limited equipment purchases, and the development of research courses.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PAR-05-127.html>
- (E) (NIGMS)

Minority Access to Research Careers (MARC) Undergraduate Student Training in Academic Research (U-STAR): MARC supports special research training opportunities for students and faculty. MARC programs also enable grantee institutions to develop and strengthen their biomedical research training capabilities. As a result, these schools are able to interest students in, and prepare them for, the pursuit of doctoral study and biomedical research careers. MARC training grants and fellowships include U-STAR institutional grants, predoctoral fellowships, faculty predoctoral and senior fellowships, and a visiting scientist program.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PAR-07-337.html>

¹¹⁰ Section 301(a)(3) of the PHS Act, as amended [42 U.S.C. 241 (a)(3)].

- (E) (NIGMS)

Ruth L. Kirschstein National Research Service Awards (NRSA) for Individual Predoctoral Fellowships to Promote Diversity in Health-Related Research:¹¹¹ The goal of this program is to provide biomedical and behavioral research and research training programs that will result in the recruitment of women and individuals from disadvantaged backgrounds (including racial and ethnic minorities) in an effort to ensure that diverse pools of highly trained scientists will be available in appropriate research areas to carry out the Nation's biomedical, behavioral, health services, and clinical research agenda. The means used is to improve the diversity of the health-related research workforce by supporting the training of predoctoral students from groups that have been shown to be underrepresented. Such candidates include individuals from underrepresented racial and ethnic groups, individuals with disabilities, and individuals from disadvantaged backgrounds. These fellowships will enhance the diversity of the biomedical, behavioral, health services, and clinical research labor force in the United States by providing opportunities for academic institutions to identify and recruit students from diverse population groups to seek graduate degrees in health-related research and apply for this fellowship.

- For more information, see <http://grants1.nih.gov/grants/guide/pa-files/PA-07-106.html>
- (E) (OD/OER, NCI, NCCAM, NCRR, NEI, NHLBI, NHGRI, NIA, NIAID, NIAMS, NIBIB, NICHD, NIDCD, NIDCR, NIDDK, NIDA, NIEHS, NIGMS, NIMH, NINDS, NINR, ODS)

NIH Research Supplements to Promote Diversity in Health-Related Research: These research supplements, formerly known as Research Supplements for Underrepresented Minorities and Research Supplements for Individuals with Disabilities, have broad eligibility criteria that include consideration of a larger number of backgrounds that could disadvantage individuals. The primary aim of this supplement is to promote diversity in the biomedical, behavioral, and clinical and social sciences research workforce through the recruitment and retention of (1) individuals from racial and ethnic groups shown by the National Science Foundation to be underrepresented in the health-related sciences, (2) individuals with disabilities, and (3) individuals from disadvantaged backgrounds. NIH recognizes a unique and compelling need to promote diversity in the biomedical, behavioral, clinical, and social sciences research workforce. NIH expects efforts to diversify the workforce to lead to (1) the recruitment of the most talented researchers from all groups, (2) an improvement in the quality of the educational and training environment, (3) a balanced perspective in the determination of research priorities, (4) an improved capacity to recruit subjects from diverse backgrounds into clinical research protocols, and (5) an improved capacity to address and eliminate health disparities.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-05-015.html>
- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-05-015.html>
- (E) (NCMHD) All NIH ICs participate in this program.

Minority Institutional Research Training Program: The purpose of this Kirschstein-NRSA training program is to support training of graduate and health professional students and individuals in postdoctoral training at minority schools that have the potential to develop meritorious training programs in cardiovascular, pulmonary, hematologic, and sleep disorders.

- For more information, see <http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-04-027.html>
- For more information, see <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-07-043.html>

¹¹¹ Section 487(a)(4) of PHS Act, as amended.

- (E) (NHLBI)

Minority Institutions' Drug Abuse Research Development Program (MIDARP): This program aims to support minority institutions wishing to develop their capacity to conduct drug abuse research. Two programs funded under this PA have focused on Hispanic issues in drug abuse. New MIDARP programs have been established at Universidad del Caribe, Hampton University, and Florida International University. MIDARP is based on a program developed approximately 20 years ago. The current program was developed according to the definition of “minority institutions” that is commonly used by NIH and other HHS agencies, for example, historic designations such as “historically Black colleges and universities” and student enrollment data. In addition, since this is a capacity development program, consideration is given to the applicant organization's history of sponsored research in drug abuse and addiction. The program will be reviewed to ensure that it furthers NIDA's science and scientific workforce needs and NIH expectations and policies regarding equitable access to research opportunities for all population groups.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PAR-05-069.html>
- (E) (NIDA)

NINR Mentored Research Scientist Development Award for Underrepresented or Disadvantaged Investigators: NINR recognizes a unique and compelling need to promote diversity in the biomedical, behavioral, clinical, and social sciences research workforce, specifically in nursing research investigators. This award program is one approach to increasing the diversity of nurse investigators and enhancing the research capabilities of historically underrepresented or disadvantaged scientists in nursing research by providing additional research career development opportunities with financial support. These awards train scientists in a mentored setting in the development of research programs, in preparation for becoming independent investigators. NINR also recognizes the lack of diversity of qualified nurse scientists in research settings. This award program seeks to address this problem by enhancing the research capabilities of underrepresented or disadvantaged nurse investigators so that these individuals may establish research laboratories and research programs in nursing science. There is abundant evidence that the research, biomedical, and health enterprise will directly benefit from this broader inclusion. The focus of activities for the awardees in this program is mentored research experience to enhance the candidate's career or to gain expertise in a research area new to the candidate.

- For more information, see <http://grants1.nih.gov/grants/guide/pa-files/PAR-05-135.html>
- (E) (NINR)

Minority Health and Health Disparities International Research Training (MHIRT) Program: In 2006, NIH provided funding for the Minority Health and Health Disparities International Research Training (MHIRT) Program, which allowed 24 academic institutions to implement international training opportunities in health disparities research for more than 150 undergraduate and graduate students. The MHIRT Program contributes to the elimination of health disparities in the United States by developing researchers who better understand health disparities issues from various international perspectives. Many MHIRT subjects are engaged in research that investigates genetic, socioeconomic, behavioral, psychosocial, and fundamental determinants of health disparities. MHIRT trainees are placed worldwide to conduct research and complete their training. The current MHIRT program expires in 2008, and a new MHIRT RFA that will build on the success of the existing program is being developed. In 2006, the majority of MHIRT research projects were focused on biomedical issues related to improving minority health and eliminating health disparities. African American and Latino (Hispanic) undergraduate and graduate students constitute the largest racial and ethnic groups participating in MHIRT training programs.

- (E) (NCMHD)

Loan Repayment Programs: To effectively promote a diverse and strong scientific workforce, it is necessary to expand and create transitioning and financial aid programs that help alleviate barriers that often discourage many students from pursuing a research career. The NIH Loan Repayment Programs address this national need by encouraging the recruitment and retention of minority and other scientists in the fields of biomedical, clinical, behavioral, and health services research. Specifically, the Loan Repayment Program for Health Disparities Research (HDR-LRP) is designed to increase the number of highly qualified health professionals in research careers focused on health disparities. Pursuant to Pub. L. No. 106-525, at least 50 percent of the awards will be made to individuals from health disparity populations. The focus of the Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds (ECR-LRP) is to increase the participation of highly qualified health professionals from disadvantaged backgrounds in clinical research careers. To develop synergies between the programs and ensure that emphasis is placed on minority health and other health disparities research efforts, the NIH will work to establish links between the LRP (HDR-LRP and ECR-LRP) and the NIH research priorities.

- (E) (NCMHD, OER)

NIH Academy: The NIH Academy provides opportunities for recent college graduates to spend a year engaged in biomedical investigation at the NIH campus. The mission of the Academy is to enhance research dedicated to the elimination of domestic health disparities through the development of a diverse cadre of biomedical researchers. Participants in this program work side by side with some of the leading scientists in the world in an environment devoted exclusively to biomedical research. Seminars and workshops round out the training experience.

- For more information, see <http://www.training.nih.gov/student/pre-irta/previewacademy.asp>
- (I) (OD/OIR)

Undergraduate Scholarship Program (UGSP): The NIH Undergraduate Scholarship Program (UGSP) for students from disadvantaged backgrounds was authorized by statute in 1994 and established in 1996. UGSP participants, as mandated under section 487D of the Public Health Service Act, receive up to \$20,000 in scholarship support to defray educational expenses. Scholarship recipients are required to be employees at the NIH IRP for 10 weeks during the summer for each year of scholarship support and to have 1 year of research employment for each year of scholarship support after their graduation. The 1-year service payback can be deferred until the receipt of a terminal degree (Ph.D., M.D., M.D/Ph.D., etc). The aim of the program is to provide students from disadvantaged backgrounds the opportunity to be trained and hired as employees in the NIH Intramural Research Program. To date, 102 students have been awarded scholarships.

- For more information, see <http://www.ugsp.nih.gov/home.asp?m=00>
- (I) (OD/OIR)

Biomedical Research Training Program for Underrepresented Minorities: This program has provided minority undergraduate, graduate, and health professional students majoring in the life sciences with the opportunity to receive training in the NHLBI intramural laboratories. This program has been renamed and re-announced as the NHLBI Biomedical Research Training Programs for Individuals from Underrepresented Groups (BRTPUG) to reflect broadened eligibility criteria for the recruitment and participation of diverse individuals in research and research training programs.

- For more information, see <http://www.nhlbi.nih.gov/funding/training/redbook/brtpug.htm>

- (E/I) NHLBI

Diversity Inventory: This work in progress is an effort to catalogue existing programs, described in the NIH Health Disparities Strategic Plan, that aim to create a culturally competent workforce by expanding opportunities for research training, career development, and institutional research capacity and infrastructure. This searchable database will be made available online as a comprehensive source of information for potential applicants or other constituents who are interested in NIH programs that are designed to promote diversity in the biomedical research workforce. This inventory will serve as a baseline for the diversity workgroup that was formed to identify and address gaps and needs in the current diversity recruitment practices.

- (O) (NIGMS, NCMHD, OER, OWH)

Research Capacity

The Minority Institution/Cancer Center Partnership (MI/CCP): The MI/CCP program, initiated in April 2000 as a collaboration between NCI and NCMHD, is focused on developing comprehensive partnerships between NCI-designated Cancer Centers and institutions where students who are underrepresented in the biomedical sciences make up a significant proportion of the enrollments as designated by the U.S. Department of Education as Minority-Serving Institutions (MSI). The aims of these partnerships are (1) to provide cancer research training and education to qualified underrepresented students and investigators to strengthen diversity in the cancer research professions and to encourage recruitment of the most talented researchers to pursue careers in research in cancer and cancer health disparities; (2) to improve the quality of the outreach, training, and educational environment for cancer research at the partnering institutions; (3) to improve the ability to recruit subjects from diverse backgrounds into clinical research protocols; and (4) to strengthen the National Cancer Program by broadening the perspective of the cancer research community in setting cancer research priorities and improving the Nation's capacity to address and eliminate health disparities.

- This example also appears in Chapter 2: *Cancer*.
- (E) (NCI)

Research Endowment Program: The NCMHD Research Endowment Program specifically targets “Section 736 [Public Health Service Act] Institutions with currently funded Programs of Excellence in Health Professions Education for Underrepresented Minority Individuals.” Congress provided for the creation of this unique program, which makes significant investments in the education and training of underrepresented minority and socioeconomically disadvantaged individuals. The Research Endowment Program is an important priority and represents one of the NCMHD cornerstone programs. NCMHD-endowed institutions are using endowment funds to enhance research capacity and infrastructure for research and training, which include strengthening teaching programs in the biomedical and behavioral sciences and related areas, making physical plant improvements, establishing endowed chairs and programs, obtaining equipment for instruction and research, enhancing student recruitment and retention, providing merit-based scholarships, recruiting and retaining faculty and developing instruction delivery systems and information technology in areas that enhance minority health and health disparities research activities, and training minority and disadvantaged scientists in the behavioral and biomedical sciences.

- (E) (NCMHD)

Research Infrastructure in Minority Institutions (RIMI) Program: The Research Infrastructure in Minority

Institutions Program (RIMI) program was originally created by the NIH National Center for Research Resources (NCRR) and the NIH Office of Research on Minority Health (ORMH), the predecessor to the NCMHD. The RIMI research infrastructure grant program is designed to strengthen the research environment of predominantly minority-serving academic institutions through grant support to develop and/or expand existing capacities for institutional and/or individual faculty initiated basic, biomedical, social, and/or behavioral research programs. The program is flexible and allows institutions to pursue, for example, research efforts that address health disparities among racial and ethnic minorities and the medically underserved, including those who reside in the Southwest Border States, rural communities, Appalachia Region, Mississippi Delta, Frontier States and urban centers of the United States. Further, the RIMI Program helps non-doctoral degree institutions to develop and enhance their capacity and competitiveness to conduct biomedical or behavioral research and develop their research infrastructure, primarily through collaborations with research-intensive universities.

- For more information, see <http://grants.nih.gov/grants/guide/rfa-files/RFA-MD-07-002.html>
- (E) (NCMHD)

Institutional Development Award (IDeA) Program: The NIH IDeA program fosters health-related research and improves the competitiveness of investigators in 23 states and Puerto Rico that historically have not received significant levels of competitive research funding from NIH. The IDeA program supports multidisciplinary centers and State-wide collaborative partnerships that increase institutions' capacity to conduct cutting-edge biomedical research. IDeA supports faculty development and enhancement of research infrastructure at institutions and also promotes collaborative community-based research, particularly in minority communities and other medically underserved communities where health disparities persist. The IDeA program supports the IDeANet initiative, which is expanding access to high-performance computational resources for data-intensive science applications and providing bioinformatics software tools and training to investigators. IDeANet began with Lariat, a pilot program that has enabled connectivity in six states (Alaska, Hawaii, Idaho, Montana, Nevada, and Wyoming). IDeANet ultimately will enable all institutions in the IDeA program, as well as subjects in NIH's Research Centers in Minority Institutions program, to engage in national and international collaborations.

- For more information, see http://www.ncrr.nih.gov/research_infrastructure/institutional_development_award
- For more information, see IDeA program evaluation GPRA goal 8.4
- This example also appears in Chapter 3: *Clinical and Translational Research*.
- (E) (NCRR) (GPRA Goal)

Research Centers in Minority Institutions (RCMI): The Research Centers in Minority Institutions (RCMI) Program began in 1985 in response to Congressional report language (House Report 98-911, on the Labor, Health and Human Services, and Education and Related Agencies Appropriation Bill for FY 1985 (July 26, 1984, pages 78-79)) directing funds to “establish research centers in those predominantly minority institutions which offer doctoral degrees in the health professions or the sciences related to health.” RCMI support includes funds to recruit established and promising researchers, acquire advanced instrumentation, modify laboratories for competitive research, and to fund core research facilities and other research support. Because many investigators at RCMI institutions study diseases that disproportionately affect minorities, NCRR support serves the dual purpose of bringing more minority scientists into mainstream research and enhancing studies of minority health. The next step in increasing the research capacity of the RCMI is to link each of them together.

- For more information, see www.ncrr.nih.gov/research%5Finfrastructure/research%5Fcenters%5Fin%5Fminority%5Finstitutions/
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (NCRR, NCMHD, NHLBI, NIA, NIAID, NIAMS, NICHD, NIDA, NIDDK, NIMH)

- (E) (NCMHD)

Resource Centers for Minority Aging Research (RCMARs): Since 1997, RCMARs have provided a venue for increasing the number of researchers who focus on the health of older minority adults, enhancing diversity in the professional workforce by mentoring minorities for careers in research on minority health among older adults, improving recruitment and retention of minority older adults in research studies, and creating culturally sensitive health measures that assess the health status of minority older adults with greater precision and increase the effectiveness of interventions designed to improve their health and well-being. An independent evaluation of the success of the RCMAR program is in progress.

- For more information, see <http://www.rcmar.ucla.edu>
- (E) (NIA)

Combating Health Disparities: NIH conducts research designed to identify racial and ethnic disparities in the causes and consequences of alcohol use disorders and to develop treatment and prevention strategies to ameliorate them. NIH contributes to all HHS and White House initiatives designed to address health disparities by (1) increasing access to and participation in HHS programs, (2) increasing the capacity of minority institutions to conduct research, and (3) promoting health data collection on racial and ethnic minority populations. For example, between 1998 and 2003, NIH increased the capacity of eight minority or minority-serving institutions to conduct alcohol research, using several cooperative agreement mechanisms. Two of these projects have ongoing activity.

- (E) (NIAAA)

Collaboration with National Coalition of Ethnic Minority Nurse Associations (NCEMNA): NIH conducts outreach activities focused on health disparities research through its relationship with the National Coalition of Ethnic Minority Nurse Associations (NCEMNA). Comprising five ethnic nurse associations, NCEMNA strives to increase the number of minority nurses in the United States and increase the amount of minority health-related research. Over the past several years, NIH has provided informational materials to NCEMNA member associations to increase awareness of NIH research opportunities for underserved investigators. In addition, NIH has participated in workshops with NCEMNA members, at which NINR senior leadership has presented information about the Institute, and NINR program directors have met individually with prospective investigators and trainees.

- (E) (NINR)

NIH Strategic Plans Pertaining to Minority Health and Health Disparities Research

NIH-Wide Strategic Plan

- [*NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities, Fiscal Years 2002-2006*](#)
CC, CSR, FIC, NCCAM, NCI, **NCMHD**, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIEHS, NIGMS, NIMH, NINDS, NINR, NLM, OAR, OBSSR, OIR, ORD, ORWH

Note: Every IC has a Strategic Plan on Health Disparities. These plans are contained with the NIH plan.

- *NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008*
(To be published; approved by the National Advisory Council on Minority Health and Health Disparities, but awaiting formal clearance)

National Institute on Allergy and Infectious Diseases (NIAID)

- [*Women's Health in the U.S.: Research on Health Issues Affecting Women \(2004\)*](#)

National Institute on Drug Abuse (NIDA)

- [*NIDA Draft Strategic Plan*](#)