

Summary of Research Activities by Disease Category

Minority Health and Health Disparities

In 1985, Secretary of Health and Human Services Margaret M. Heckler issued the [Report of the Secretary's Task Force on Black and Minority Health](#). This landmark report revealed the disproportionate burden of disease, disability, and death experienced by African Americans, Hispanics, Native Americans, and Asian/Pacific Islanders in the United States. In calling attention to this national crisis, Secretary Heckler elevated the elimination of health disparities to an important national priority and validated earlier concerns expressed in the Healthy People 1979 report. By 1990, the Office of Minority Programs was created administratively within the Office of the Director, NIH. Congressional legislation followed in 1993 that established the Office of Research on Minority Health (ORMH) and charged it with improving the health of vulnerable populations. With a small budget and no grant-making authority, ORMH partnered with a select group of NIH ICs to support vital programs focused on basic research, health education, and infrastructure development. A broadened and ambitious agenda for the field has been advanced since FY 2000 when Congress established the National Center on Minority Health and Health Disparities (NCMHD).

Much has been accomplished over the years. Scientists are beginning to understand the genetic underpinnings of certain diseases such as systemic lupus erythematosus (lupus) and chronic kidney disease. NIH health education campaigns currently are improving the health literacy of vulnerable communities in critical areas such as cardiovascular disease and stroke, diabetes, cancer, HIV/AIDS, diseases of the eye, lupus, and Alzheimer's disease. Comprehensive Sickle Cell Centers are supporting multidisciplinary programs of basic, applied, and clinical research and also are providing patient services in diagnosis, counseling, and education concerning sickle cell disease and related disorders.

By mid-century, the U.S. Census Bureau projects that the Nation will be more racially and ethnically diverse. Racial/ethnic minorities, now roughly one-third of the U.S. population, are expected to become the majority population in 2042 and 54 percent of the U.S. population by 2050.^{156,157} As the diversity of the U.S. population and the burden of diseases continue to increase, biomedical research to understand, predict, prevent, and treat diseases disproportionately burdening vulnerable populations is critical. NIH is at the forefront of confronting this challenge.

¹⁵⁶ Bernstein R, Edwards T. "An Older and More Diverse Nation by Midcentury". U.S. Census Bureau News. August 14, 2008. Available at <http://www.census.gov/Press-Release/www/releases/archives/population/012496.html>. Accessed September 16, 2009.

¹⁵⁷ Table 4. Projections of the Population by Sex, Race, and Hispanic Origin for the United States: 2010 to 2050 (NP 2008-T4). Source: Population Division, U.S. Census Bureau. Release Date: August 14, 2008. Available at: <http://www.census.gov/population/www/projections/files/nation/summary/np2008-t4.xls>. Accessed September 16, 2009.

Introduction

Scientific and technological discoveries throughout the 20th century have improved the overall health of the Nation and generated hope for happier, healthier, and longer lives for all. However, some segments of the U.S. population continue to experience elevated morbidity and mortality, disproportionate incidence of disease and disability, and adverse outcomes in cancer, cardiovascular disease, diabetes, HIV/AIDS, infant mortality, and certain other conditions. These disparities in health are most visible in racial/ethnic minority groups, in individuals from socioeconomically disadvantaged backgrounds, and in people living in medically underserved areas including rural communities.

NIH has devoted considerable resources to characterizing the root causes of health disparities. As a result of these efforts, a complex and multifactorial web of interconnected and overlapping factors (i.e., biological, behavioral, environmental, and societal) has begun to emerge. For example, poverty and lack of education correlate with poor health and lower life expectancy; moreover, discrimination based on racial, ethnic, and linguistic differences in the United States not only triggers biological stress, but also creates a barrier to accessing high-quality health care. In addition, some groups are genetically susceptible to certain diseases, and when this inherited biological vulnerability combines with adverse social and/or environmental factors (e.g., poor diet, pollution, economic stress), these groups exhibit poorer health outcomes. These are some of the interrelated factors that contribute to the existence of health disparities. Confronting this formidable challenge is at the heart of the vigorous efforts NIH is undertaking to make advances in science that will translate into effective prevention and treatment interventions.

In keeping with its role as the Nation's steward of biomedical and behavioral research, NIH is firmly committed to ultimately eliminating health disparities in the United States. Since the issuance of the [*Black and Minority Health Report*](#) in 1985, NIH has incorporated the goals of improved health for all Americans and the elimination of health disparities in its support of biomedical and behavioral research, research training, research capacity-building, outreach, and research and health information dissemination. Many of these activities are multidisciplinary collaborations involving several NIH ICs or NIH and non-Federal organizations. These efforts not only have advanced health disparities research, but also have facilitated communications among stakeholders and moved the field forward exponentially during the last 24 years.

NIH programs to address minority health and health disparities are guided by the *NIH Health Disparities Strategic Plan and Budget*. NIH conducts and supports research, training, dissemination of information, and other programs that address the health conditions of racial/ethnic minorities and other populations experiencing health disparities. This comprehensive document, which sets the overarching principles for the NIH health disparities agenda, 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 sensitive and 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 and health disparities strategic plan, and those efforts are captured within this plan.

In December 2008, NIH convened the first trans-NIH health disparities summit to showcase the collective investment, contributions, and partnerships in health disparities research among NIH ICs and other Federal government agencies, and within the private sector. This 3-day forum, *The NIH Science of Eliminating Health Disparities Summit*, was structured into 3 multitopic plenary sessions and 5 distinct breakout session tracks consisting of both oral and poster presentations of pioneering health disparities research. The third day closed with a town hall meeting. More than 4,000 researchers, scientists (including those in the social, behavioral, environmental, and political sciences), public health professionals, community leaders, health advocates, and stakeholders with an interest in health disparities attended to (a) assess current advances in health disparities research and interventions, (b) examine gaps in research and data, (c) explore conceptual frameworks and theories, and (d) provide recommendations to NIH for advancing health disparities research through the translation of science into practice and effective policy.

In 2008, more than 4,000 scientists, public health professionals, community leaders, health advocates, and stakeholders with an interest in health disparities gathered to assess current advances in health disparities research and interventions, examine gaps in research and data, explore conceptual frameworks and theories, and provide recommendations to NIH for advancing health disparities research. The recommendations that emerged from this conference will help to continue shaping the NIH health disparities research agenda and specifically inform the next iteration of the NIH Health

A *Science, Policy, and Practice* framework for addressing health disparities was proposed as an overarching, organizational construct to promote advances to identify ways to bridge science, practice, and policy and to shape future research. Researchers focused attention on the links between biological and nonbiological determinants of health in health disparity populations. Participants particularly stressed (1) the critical need for health and health care reform; (2) the adoption of a life-course approach to addressing disparities and the social determinants of health; (3) the integration of eliminating health disparities as a goal not only within public health policies, but also within social, environmental, educational, and institutional policies that are known to have a direct impact on health; and (4) the need for partnerships, collaborations, and community engagement in health disparities research.

The summit set some broad goals for the next decade for the NIH health disparities research agenda: (1) enhance trans-NIH collaborations in health disparities research and develop stronger Federal collaborations that will advance both science and research while providing effective methods to measure outcomes; (2) adopt a research framework at the intersection of science, practice, and policy that includes the biological and nonbiological determinants of health; (3) embrace a research process that recognizes and acknowledges the unique strengths of partnerships, collaborations, community engagement, and transdisciplinary efforts; (4) promote outreach in the news media; and (5) continue to support capacity-building and infrastructure development to nurture a research training pipeline that produces a highly motivated, diverse workforce of researchers dedicated to eliminating our Nation's most critical health disparities. These recommendations will inform the next version of the *NIH Health Disparities Strategic Plan for FYs 2009-2013*.

Burden of Illness and Related Health Statistics

Health disparities affecting racial/ethnic minorities and other medically underserved populations are seen across a broad spectrum of diseases and conditions. They represent one of the most persistent public health challenges in the United States. Research findings consistently have shown that many health disparity populations also are less likely than most of the majority population to receive needed health care services, including clinically necessary procedures. Health disparities frequently are associated with differences in socioeconomic status (SES) and tend to diminish significantly and, in a few cases, disappear when SES factors are controlled. Nevertheless, some racial/ethnic disparities remain even after adjusting for SES differences and other factors related to health care access.¹⁵⁸ For details on the depth and breadth of this burden, see the following table of data, presented by disease and condition.

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About Various Health Disparities Affecting Racial and Ethnic Minorities and Other Medically Underserved Populations in the United States

Cancer: The variation in cancer burden among various medically underserved, racial/ethnic minority, and low-income populations indicates statistically significant disparities between

populations and within subpopulations. For example, African Americans are more likely to develop and die from cancer than any other racial/ethnic group. The cancer death rate for African American males and African American females is 36 percent and 17 percent higher than among white males and white females, respectively. The 5-year survival rate for all cancers combined is lower for African Americans (58 percent) than for whites (68 percent). Hispanics, Asian Americans, and Pacific Islanders have a lower incidence for some common cancers, but have appreciably higher rates of cancers associated with infection, such as uterine, cervical, liver, and stomach cancer. For Asian American subpopulations, cervical cancer among Vietnamese women is three times higher than among Chinese and Japanese women. Mortality rates for renal cancer in American Indians and Alaska Native men and women are higher than in any other racial/ethnic population.¹⁵⁹ Cancer patients with low SES have more advanced cancers at diagnosis, receive less aggressive treatment, and have higher risk of dying in the 5 years following cancer diagnosis.¹⁶⁰ Women who lack health insurance have the lowest rates of mammography screening (24 percent). Similarly, there is persistent underuse of the Pap test among women who are uninsured, recent immigrants, and those with low education.¹⁶¹

Coronary Heart Disease and Stroke: Despite remarkable reductions in cardiovascular morbidity and mortality during the past 4 decades, some racial/ethnic minorities still bear a disproportionate share of the burden. Rates of heart disease have been consistently higher for the African American population than for whites. In 2005, coronary heart disease age-adjusted death rates for African American men (329.8 per 100,000) and African American women (228.3 per 100,000) were 28 and 36 percent higher than for white men and women, respectively.¹⁶² In the period 2003-2006, stroke affected 3.3 percent of the African American population under 75 years of age, compared to 2 percent of whites under age 75.¹⁶³ Age-adjusted death rates for stroke were 46 percent higher in the black/African American population than the white population.¹⁶⁴ Death certificate data from 2002 show that mean age at stroke death was younger among African Americans, American Indians/Alaska Natives, and Asians/Pacific Islanders than among whites. The mean age at stroke death also was younger among Hispanics than non-Hispanics.¹⁶⁵

HIV/AIDS: In 2007, blacks comprised approximately 13 percent of the U.S. population, but accounted for 48 percent of all persons living with HIV/AIDS in the 34 states with long-term, confidential, name-based HIV reporting. In 2007, HIV/AIDS rates (per 100,000 population) were 76.7 among black/African Americans, 34.6 among Native Hawaiian/Other Pacific Islanders, 27.7 among Hispanics, 12.8 among American Indians/Alaska Natives, 9.2 among whites, and 7.7 among Asians.¹⁶⁶ Certain subpopulations are disproportionately affected. Among females—for whom the predominant transmission category was high-risk heterosexual contact—the HIV incidence rate for black/African Americans is 14.7 times that of whites, and for Hispanics it was 3.8 times the rate.¹⁶⁷ In general, blacks/African Americans, especially black/African American males, and men having sex with men (of all races) were represented disproportionately in 2006 among persons with new HIV infection.¹⁶⁸ In 2004, Puerto Rico was among the top 10 U.S. states and territories with the highest number of AIDS cases, with an estimated 10,000 persons living with AIDS. The rate for adults and adolescents in Puerto Rico with AIDS was estimated to be 324 per 100,000 population.¹⁶⁹

Infant Mortality: While the overall infant mortality rate decreased 2.6 percent between 2005 and 2006, a disparity in infant mortality rates between black/African Americans (13.3 deaths per 1,000 live births) and whites (5.6 deaths per 1,000 live births) remained.¹⁷⁰ For Hispanic Americans, the infant mortality rate varies among subpopulations. In 2005, the rate for Cubans was 4.4 per 1,000 live births, while the rate for Puerto Ricans was 8.3 per 1,000 live births. Puerto Ricans have a 40 percent higher infant mortality than that of non-Hispanic whites.¹⁷¹ Rates of premature birth also are higher for racial/ethnic minority groups. Preliminary data for 2007 show that 18.3 percent of non-Hispanic black newborns and 13.9 percent of American Indian newborns were born preterm compared to 11.5 percent of non-Hispanic white newborns and 10.9 percent of Asian or Pacific Islander newborns. For non-Hispanic blacks, there also is a higher percentage of low-birth-weight babies. Preliminary 2007 data show that 13.8 percent of non-Hispanic black babies were born at

low birth weight, compared with 7.2 percent of non-Hispanic white babies.¹⁷²

Type 2 Diabetes: According to 2004-2006 national survey data, racial/ethnic disparities in type 2 diabetes exist for persons ages 20 years or older. American Indian/Alaska Natives and black/African Americans are affected disproportionately. During that timeframe, 15 percent of the American Indian/Alaska Native population¹⁷³ and 11.8 percent of the non-Hispanic black/African American population were diagnosed with diabetes compared to 6.6 percent of non-Hispanic whites, 7.5 percent of Asian Americans, and 10.4 percent of Hispanics.¹⁷⁴ The rate of diabetes is particularly striking among the Pima Indians. One in 2 adult Pima Indians has diabetes, and among those with diabetes, 95 percent are overweight.¹⁷⁵ Among Hispanics, there is marked heterogeneity in diabetes rates for the different Hispanic subgroups, namely, 8.2 percent for Cubans, 11.9 percent for Mexican Americans, and 12.6 percent for Puerto Ricans.¹⁷⁶ Hispanics also experience complications of diabetes disproportionately. Hispanics of all races experienced more age-adjusted years of potential life lost before age 75 per 100,000 population than non-Hispanic whites for diabetes (41 percent more) and other causes of death such as stroke (18 percent more) in 2001.¹⁷⁷ In 2005, Hispanics were 1.6 times as likely to die from diabetes as non-Hispanic whites, and also had higher rates of obesity and hypertension.¹⁷⁸ Similar to the occurrence in adults, African American, Native American, and Hispanic children and adolescents are disproportionately afflicted with type 2 diabetes.¹⁷⁹

Asthma: The prevalence of asthma among non-Hispanic blacks was approximately 30 percent higher than among non-Hispanic whites and approximately double that of Hispanics in 2002.¹⁸⁰ According to data on U.S. children from the *2007 National Health Interview Survey*, non-Hispanic black children, poor children, and children who were reported to be in poor health, had higher prevalence of asthma. Specifically, non-Hispanic black children were more likely to have ever been diagnosed with asthma (20 percent ever diagnosed) than Hispanic (13 percent) or non-Hispanic white children (11 percent). Asthma was more likely to be diagnosed in children from poor families (17 percent) than in children from non-poor families (12 percent), and in children in poor health (41 percent) than in children in excellent or very good health (11 percent).¹⁸¹ In 2005, for Hispanic subpopulations, specifically Puerto Ricans, the asthma prevalence rate was 125 percent higher than that of non-Hispanic whites and 80 percent higher than non-Hispanic blacks. Moreover, Puerto Ricans had the highest rate of asthma attacks in the prior year, which was 140 percent higher than that of non-Hispanic whites. American Indians and Alaska Natives had a 40 percent higher rate than non-Hispanic whites.¹⁸²

Mental Illness: Disease burden associated with mental disorders also varies across racial/ethnic minority populations. Native Americans and Alaska Natives, for example, not only have disproportionately higher rates of depression, but also experience higher rates of suicide than do other populations.¹⁸³ Suicide rates among American Indian/Alaskan Native adolescents and young adults aged 15 to 34 (21.7 per 100,000) are 2.2 times higher than the national average for that age group.¹⁸⁴ 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 longer.¹⁸⁵ Young African Americans—specifically those between the ages of 10 and 14—experienced a dramatic increase in suicide rates between 1980 and 1995; the rate increased 233 percent vs. 120 percent for their non-Hispanic white counterparts. Moreover, African Americans are overrepresented in populations at high risk for mental illness, including homeless and incarcerated populations, children in foster care and the child welfare system, and persons exposed to violence.¹⁸⁶ Differences also exist within racial/ethnic 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 immigrants.¹⁸⁷ These findings also vary across subgroups.¹⁸⁸

Eye Diseases: Disparities in eye diseases are experienced among racial/ethnic minorities. Glaucoma is a blinding visual disorder resulting from damage to the optic nerve. In 2000, approximately 2.2 million people ages 40 years or older were estimated to have the most common

form of glaucoma, and it is projected that by 2020, this will grow to 3.4 million. Glaucoma is the leading cause of irreversible blindness in African Americans and Hispanics, and is almost three times more common in African Americans compared to whites. Among Hispanics, the prevalence of glaucoma is seen to rise rapidly after age 65.^{189,190}

Dental Caries, Oral and Pharyngeal Cancer, and Periodontal Diseases: The [U.S. Surgeon General's Report: Oral Health in America](#)¹⁹¹ and recent epidemiologic studies document that underserved and racial/ethnic minority populations experience disproportionate burdens of dental caries, oral and pharyngeal cancer, and periodontal diseases.^{192,193} Dental caries, an infectious disease that affects quality of life, is one of the most prevalent health conditions in the United States. The distribution of dental caries in primary teeth by race/ethnicity is uneven, with 55 percent of Mexican American and 43 percent of African American children ages 2 to 11 experiencing this disease compared with 39 percent of whites, according to the *National Health and Nutrition Examination Survey (NHANES), 1999-2004*. Comparable differences are seen between poor and more affluent children (54 percent vs. 32 percent, respectively). Among poor children, more than half of this decay is untreated.¹⁹⁴

The American Cancer Society recently estimated that approximately 31,000 new cases and 7,320 deaths per year were attributable to oral cavity and pharyngeal cancer. The prognosis of these cancers is poor, especially when they are detected at a late stage. Black/African American males and subgroups of Hispanic male populations are known to be at increased risk for late-stage malignancies that are less amenable to treatment and have poorer survival rates. For white males the 5-year survival rate for oropharyngeal cancer is 61 percent compared to 38 percent for black/African American males.¹⁹⁵

Health disparity populations are more likely to experience periodontal disease, which range from mild forms of gingivitis to severe forms of periodontitis. For example, black/African Americans are more likely than whites to have periodontitis. Similar levels of inequalities in periodontal disease also exist by education level and poverty level.¹⁹⁶

Systemic Lupus Erythematosus (Lupus): Lupus is a serious and potentially fatal autoimmune disease, often occurring in women of child-bearing age. It can affect many parts of the body, including the joints, skin, kidneys, heart, lungs, blood vessels, and brain. People of all races can have lupus, but incidence in African American women is three times higher than in white women.¹⁹⁷ They tend to develop the disease at a younger age than white women, and to develop more serious complications.¹⁹⁸ Nine times more women than men have lupus, and it also is more common in Hispanic, Asian, and Native American women.¹⁹⁹

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

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NIH Funding for Minority Health and Health Disparities Research

Actual NIH funding support levels for research on minority health were [\\$2,396](#) million in FY 2008, and [\\$2,592](#) million and [\\$378](#) million in FY 2009, respectively, for non-ARRA (regular appropriations) and ARRA (Recovery Act appropriations). Actual NIH funding support levels for health disparities research were [\\$2,614](#) million in FY 2008, and [\\$2,806](#) million and [\\$434](#) million in FY 2009, respectively, for non-ARRA and ARRA. There is substantial overlap in these funding figures. NIH funding for minority health and health disparities does not follow the standard RCDC process. These categories assign project funding according to populations tracked by gender or ethnicity. The databases used to track gender/ethnicity are complex and currently not compatible with the RCDC system. The table at the end of this chapter indicates the funding involved in this investment (see *Estimates of Funding for Various Research, Condition, and Disease Categories*.)

Summary of NIH Activities

NIH's commitment to reduce and ultimately eliminate health disparities in the United States is manifested in a wide variety of programs focused on: (1) Research, (2) Outreach, (3) Research/Outreach, (4) Research Training, and (5) Research Capacity. 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, many NIH programs are highly collaborative and cross-disciplinary, both within NIH and in partnership with external organizations. This section illustrates some of the currently funded initiatives.

Research

Basic, Clinical and Translational Research

NIH conducts and supports basic, clinical, and translational research designed to explain the

relationship between disease and disparities, and improve patient quality of life. As knowledge increasingly is gained about the causes, mechanisms, natural histories, prevention, and treatment of diseases associated with known disparities, the ability to move important scientific discoveries effectively and efficiently from the bench to the bedside, and from the bedside to the community, will be a vital element in the ongoing campaign to reduce and eliminate health disparities in the United States. Research describing genetic vulnerabilities to specific diseases among specific populations is becoming a particularly fruitful area. Several initiatives are employing the rapidly advancing technological tools of modern genomics, such as genome-wide association studies (GWAS), linkage analysis, and direct sequencing, to discover the genetic variations involved in susceptibility to disease (also see the section on *Genomics* in Chapter 3 for more information about GWAS).

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For example, NIH support of research, disease registries, biological sample repositories, and collaborative initiatives with European researchers has advanced significantly our understanding of the genetic underpinnings of lupus. Lupus is an autoimmune disease that strikes women predominantly (nine times as often as men), and African American women at a rate three times that of white women. Numerous lupus risk genes have been identified recently, reflecting the complex expression of the disease, which varies from patient to patient. Among other translational efforts, methods are being developed to analyze individual patients' blood samples to group disease-specific variations in gene expression according to pathogenic mechanisms, which may be used to predict flares of lupus activity and eventually help guide individualized treatment.

The [Centers of Research Translation \(CORT\)](#) program is designed to help translate basic research discoveries into clinical trials for diagnostic approaches and treatments. One of the currently funded centers focuses on scleroderma, a disabling disease characterized by hardening of tissues in many parts of the body, including skin, internal organs, and blood vessels. There is a higher prevalence in some American Indian populations. Using functional genomics and gene networks, investigators at the center are studying the molecular basis of the disease to understand its underlying causes. Two other centers are focused on lupus research: one on the role of different cell types in the origin and development of lupus, and the other on examining the genetic underpinnings of the disease.

Chronic kidney disease (CKD) and diabetes also are the focus of intensive research efforts to associate genetic variations with increased disease risk. Scientists recently have identified a genetic region strongly associated with CKD that arises as a consequence of diseases other than diabetes, such as hypertension and HIV-associated kidney disease in African Americans. Another study is devoted to identifying and validating biomarkers and risk assessment tools for kidney function, injury, and disease progression in CKD patients, which will help assess disease risk and progression, and aid in early diagnosis. To help unravel the complex interactions between genes and environment involved with both type 1 and type 2 diabetes, NIH is supporting the [Type 1 Diabetes Genetics Consortium](#) and several major grants to study the genetics of type 2 diabetes. Studies have identified numerous genetic regions linked to both forms of the disease, while other studies concentrate on refining our understanding of how these genetic variations affect disease risk, particularly in specific racial/ethnic groups disproportionately affected by type 2 diabetes.

Characterizing gene-environment interaction to better understand disease risk factors also is at the heart of the [Genetics of Coronary Artery Disease in Alaska Natives Study](#). The study not only is discovering relevant genes through genomic studies in a cohort of large Alaska Native families, but also is exploring the impact of changing lifestyle and diet on disease risk. Researchers have described

rapidly increasing risk for coronary artery disease as villagers' lifestyles and diets have become increasingly westernized.

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The AIDS pandemic has proven to be one of the most significant challenges faced by the biomedical research community. In the United States, this devastating illness has heavily burdened racial and ethnic minorities and other medically underserved populations. NIH has made a significant investment in research to explain basic HIV biology. The NIH-sponsored Center for AIDS Health Disparities Research (CAHDR) at Meharry Medical College currently is investigating the biological basis for HIV/AIDS disparities among racial and ethnic groups. Recent CAHDR basic and translational research have explained the role of cholesterol in HIV entry into and replication within the cell. CAHDR investigators also have identified a microbial agent, betacyclodextrin (BCD), that can inactivate HIV and also make cells resistant to infection by removing cholesterol from the cell. This important discovery holds the hope that antimicrobial compounds such as BCD may be used as microbicides to protect women against HIV infection. The NIH-funded Meharry Translational Research Center will continue to investigate the varied reliance on cholesterol for survival and its implications for developing potential new treatments for HIV infections and for treating AIDS patients with lipid imbalances.

Epidemiological/Population Research

Epidemiological and population research contribute significantly to efforts to eradicate health disparities by providing important knowledge designed to help identify, quantify, and characterize health disparities among populations; to test and monitor the effectiveness of potential interventions; and to monitor the health status of racial/ethnic minority groups. NIH fosters considerable research in this area across a wide range of conditions, disciplines, and health disparities populations.

For example, the NIH [Inner-City Asthma Consortium \(ICAC\)](#), launched in 2002, consists of 10 academic clinical centers designed to develop and carry out a long-range scientific plan to prevent asthma and reduce its severity in children living in the inner city where the prevalence and severity of asthma is particularly high. ICAC members are investigating the mechanisms underlying the onset and progression of asthma in this population, and are conducting research to develop diagnostic and prognostic biomarkers. ICAC researchers also are conducting clinical trials of promising immune-based therapies.

[Reasons for Geographic and Racial Differences in Stroke \(REGARDS\) Study](#) is an observational study to explore the role of racial/ethnic and geographic differences on stroke risk factor prevalence and stroke incidence and mortality. Recruitment of the main REGARDS cohort was completed in 2007, with more than 30,000 participants enrolled. The group is 41 percent African American and 59 percent white, 55 percent female and 45 percent male. A number of important findings already are emerging that partially explain why African Americans and people in the so-called "Stroke Belt" in the southeastern United States are at higher risk of dying from stroke.

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risk of dying from stroke.

The [Collaborative Psychiatric Epidemiology Surveys \(CPES\)](#) are large national surveys exploring the prevalence and characteristics of mental health disorders in the United States, and are contributing important information on disparities in the incidence of psychiatric illnesses and mental health service usage and access among racial/ethnic minorities. This effort includes the National Comorbidity Survey-Replication, the National Latino and Asian American Study, and the National Survey of American Life (NSAL), which focuses on the African American population. An important [recent finding](#) from the CPES NSAL study is that African American teens, especially girls, are at increased risk for suicide attempts, even if they have not been diagnosed with a mental disorder.²⁰⁰ Such important results will lead to the development of interventions targeted at the populations at highest risk and to more efficient utilization of precious resources.

NIH has established a large-scale prospective study to elucidate the role of prenatal alcohol consumption and other maternal risk factors in three devastating pregnancy outcomes—fetal alcohol syndrome, sudden infant death syndrome, and stillbirth. [The Prenatal Alcohol, Sudden Infant Death Syndrome \(SIDS\), and Stillbirth \(PASS\) Research Network](#) will follow 12,000 pregnant, high-risk, American Indian and South African women and their infants until the infants are 12 months old. Since fetal alcohol syndrome was first recognized in 1970, NIH has supported epidemiological and clinical research in this area.

²⁰⁰ For more information, see www.nimh.nih.gov/science-news/2009/black-teens-especially-girls-at-high-risk-for-suicide-attempts.shtml.

Outreach

NIH outreach initiatives encompass a wide range of endeavors, including communications and education programs, partnerships and collaborations with public and private organizations, and enhancement and expansion of access to information and services among disadvantaged populations. Outreach initiatives span many forms of activity, from creation of a new slogan to promote early stroke awareness, to efforts to disseminate science-based oral health information to specific populations, to health information outreach initiatives targeting high school students, and to a new, decade-long program devoted to environmental public health. They also address diverse stakeholder audiences, including students, patients, health care providers, public health educators and officials, policymakers, professional and patient advocacy organizations, and community-based groups. Information and interventions may target specific diseases and conditions such as HIV/AIDS, diabetes, digestive tract diseases, and SIDS, or they may be oriented toward a particular health disparities population subgroup, or both. These include a variety of NIH health information websites, several of which are available in Spanish (e.g., <http://www.cancer.gov/espanol>, <http://medlineplus.gov/spanish/>, <http://aidsinfo.nih.gov/infoSIDA/>).

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"Stroke strikes fast. You should too. Call 9-1-1." is the new action-oriented message being promoted by NIH in coordination with the Brain Attack Coalition, launched in May 2009 during Stroke Awareness Month.²⁰¹ This important educational initiative is just one small part of a grassroots educational campaign, [Know Stroke in the Community](#), being conducted by NIH and CDC. The program encourages community leaders to become "Stroke Champions" and educate their neighbors about the

signs and symptoms of stroke. It focuses on reaching African Americans, Hispanics, and seniors at high risk for stroke, as well as their family members, caregivers, and health care providers. As of the summer of 2009, Know Stroke has been launched in 12 cities and has educated 184 Stroke Champions who have conducted more than 600 community events. In 2007, NIH initiated a related stroke outreach program specifically targeted at Hispanics, who have a higher rate of risk factors for stroke and often face cultural and/or language barriers to prompt treatment, which is so crucial to achieving a positive outcome in the event of a stroke. The program's key component is a toolkit, *Ataque cerebral: conozca los síntomas y actúe a tiempo* (*Know Stroke. Know the Signs. Act in Time*), which can be used by *promotores de salud* (lay health educators) in *charlas* (health talks) to educate communities about the signs of stroke and the importance of calling 911 promptly to receive appropriate medical treatment.

NIH outreach also is tailored to meet the needs of specific groups or it may be designed to address the group itself or those who provide treatment or services to a group. Science-based oral health information disseminated by two NIH programs illustrates this point. A new Spanish-language website increases access to science-based oral health information among Hispanics. The site was recently tested in two cities to ensure that it is understandable, credible, and attractive to the intended audience of Spanish-dominant and bilingual Hispanics with backgrounds from different countries of origin and with varying levels of education. Dentists, dental hygienists, and caregivers have learned how to better serve the oral health needs of people with developmental disabilities through an online continuing education (CE) program called [Practical Oral Care for People with Developmental Disabilities](#). The modules have proven so popular that NIH has extended the CE credit through 2011.

Sometimes outreach can be as simple as making new, innovative connections to reach particular audiences, but naturally, such initiatives often can be quite ambitious at the same time. Take the [Science Education Partnership Award \(SEPA\)](#) Program, which fosters relationships among educators, museum curators, and medical researchers to encourage the development of hands-on, inquiry-based curricula that inform students about timely issues such as obesity, diabetes, stem cells, and emerging infectious diseases. Through its exhibits at science centers and museums, SEPA introduces tens of thousands of young students, including those from underserved communities, per year to careers in the biomedical sciences. In FY 2008, SEPA supported 68 projects, 50 of which were for middle and high school students, and 18 were based at science centers and museums. [Spectrum: Building Pathways to Biomedical Research Careers for Girls and Women](#), a SEPA-funded program at San Francisco State University, connected girls of color in high school and middle school with women of color who are biomedical research trainees or faculty members and provided them and other underrepresented groups with materials about biomedical research careers.

NIH also brings timely and important health information to students in rural schools, and ultimately to their communities. The [Peer Tutor High School Program in the Lower Rio Grande Valley of Texas](#), a school-based collaborative outreach program, is training high school Peer Tutors in the National Library of Medicine's online health resources, and then empowering them to teach other students and to disseminate health information to the local community. The majority of peer tutors and students in participating schools are Hispanic. Initiated more than 5 years ago, this program has trained more than 50 peer tutors who have conducted outreach to more than 2,500 high school students in the Lower Rio Grande Valley. The program has engaged the Biblioteca Las Américas high school librarians in a leadership role to bring together students, faculty, administrators, and community leaders in promoting important online access to useful health information. This program currently is being replicated in other health disparity communities. Another unique program uses advanced Internet connectivity to electronically bring together Alaska Native students from a remote area of Alaska with predominantly Hispanic and African American students in inner-city Los Angeles for curriculum-based classroom lectures by scientists and information-sharing among the students.

Partnerships play a major role in NIH outreach. Working with religious organizations has been a useful method of reaching rural, minority, and other underserved groups. NIH sponsors the [Consumer Health](#)

[Resource Information Service \(CHRIS\) Program](#) with church ministries in Tennessee to improve information access and health literacy related to the high incidence of disease in those communities. A long-standing NIH partnership with the United Negro College Fund Special Programs Corporation promotes capacity-building, improved information access, and community outreach on Historically Black Colleges and University (HBCU) campuses and surrounding communities.

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The NIH [Partnerships for Environmental Public Health Program \(PEPH\)](#), a 10-year umbrella program, currently is bringing together scientists, community members, educators, health care providers, public health officials, and policymakers to promote science-based investigations of environmental health threats that affect communities at local, regional, and national levels. By promoting environmental public health research and dissemination over the next decade, NIH will lead the effort to educate vulnerable populations about the dangers of exposure to occupational or environmental hazards.

²⁰¹ For more information, see

http://www.ninds.nih.gov/news_and_events/news_articles/pressrelease_stroke_awareness.htm.

Research/Outreach

NIH frequently supports projects that incorporate a mix of elements devoted to both research and outreach. These activities often intermingle, and may involve one or more outreach elements such as education, awareness, recruitment of study/clinical trial participants, and a variety of clinical and preventive interventions, often translational in nature. In many initiatives, information and interventions are provided 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. Community-based participatory research (CBPR) is an increasingly important component of many such projects. The CBPR approach ensures that various stakeholders (community members, key organizational representatives, health care delivery team members, decisionmakers, and researchers) participate as full partners in scientific research to improve the health of communities.

NIH is supporting the development, implementation, and evaluation of intervention research by using CBPR principles and methods to target diseases of major public health interest such as obesity, diabetes, cancer, hypertension, HIV/AIDS, and mental health issues such as suicide and alcohol abuse in health disparity communities. The [NCMHD Community-Based Participatory Research Program](#) promotes participatory research collaborations that are equal partnerships between community organizations and members of the research community in all stages of the research process. This long-term program supports a 3-year planning phase, a 5-year intervention phase, and a 3-year dissemination phase. The initiative began in FY 2005 with the award of 25 3-year research planning grants. In FY 2008, 40 5-year intervention research grants were awarded. Competitive 3-year dissemination grants will be made in 2013.

CBPR principles as they apply to health disparities research are the driving force behind the [NCMHD Centers of Excellence Program](#). Since its inception, this congressionally mandated program has created hundreds of unique partnerships to improve the health of racial/ethnic minorities and other health disparity populations by forging ties with hospitals, tribal groups, health plans, health centers,

community- and faith-based organizations, civic and nonprofit health organizations, and local, city, and state governments. The centers and their associated grants now are located in 32 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. NIH supported 49 centers in FY 2008 and 51 in FY 2009; in May 2009, NIH issued an RFA using ARRA funds to support centers with a 2-year project period, as opposed to the traditional 5 years. The Centers of Excellence, with their community partners, have contributed substantially to scientific knowledge and lay understanding of health disparities. Other CBPR programs funded by NIH include the [Community Networks Program to Reduce Cancer Health Disparities Through Education, Research and Training \(CNP\)](#). A total of 25 institutions were funded under this 5-year program to reduce cancer disparities in racial/ethnic minorities and underserved populations by increasing access to and use of beneficial biomedical procedures in primary and secondary prevention, and to develop a cadre of well-trained researchers who will continue to reduce disparities in communities.

In some instances, programs combining research and outreach will target a particular problem in a particular population. That was the case in a recent initiative studying the oral health of rural California Latino preschoolers. Researchers explored how the interactions among family, community, providers, and regulators led to oral health disparities among this cohort of children. For example, caregivers were found to not always recognize signs of tooth decay among their children. Access to care was difficult due to fluctuating insurance eligibility, lack of public transportation, and other factors. There also was a lack of dentists willing to serve rural low-income populations. The empirical research associated with these and many more observations has contributed to understanding that multiple intersecting factors at numerous levels should inform intervention research targeted to the individual, the community, and society. Another example of this is the [Patient Navigation Research Program \(PNRP\)](#), which is designed to examine effective ways to engage health providers and health systems to ensure that racial/ethnic minority and underserved Americans receive appropriate cancer screening, diagnosis, and treatment in a timely manner. Although anyone may benefit from Patient Navigation services, the primary participants for this research program are populations experiencing cancer health disparities, such as racial/ethnic minorities, individuals with lower SES, and residents of rural areas.

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Many programs use important research findings as the basis for designing effective outreach efforts and targeted interventions. For example, NIH, along with multiple Federal agencies and health and social service professionals, systematically is moving science-based substance abuse treatment interventions into the criminal justice system, where improvements are sorely needed. Research has suggested that prisoners who receive prison-based treatment may be more likely to remain drug-free upon their release. Similarly, new research has shown that among HIV-positive prisoners who begin treatment in prison, simply providing them help with paperwork to receive their medications can promote greater continuity of HIV pharmacotherapy upon release. In this instance, research informing outreach may reduce drug use and criminal recidivism, and help limit the spread of HIV in communities—all potentially significant social and public health accomplishments.

Research Training

To ensure that the next generation of biomedical scientists is broadly diverse and to build upon the substantial existing body of knowledge regarding the causes and potential amelioration of minority health and health disparities, NIH supports many research training programs, both intramural and

extramural. NIH research training programs promote diversity in the biomedical research workforce to increase the pool of scientists from diverse backgrounds underrepresented in this field, including persons from disadvantaged backgrounds, individuals from racial/ethnic minority groups, and persons with disabilities.

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A FY 2008 program announcement, [Research Supplements to Promote Diversity in Health-Related Research](#), launched an NIH-wide initiative to promote diversity in the biomedical, behavioral, clinical, and social sciences research workforce. This program is designed to provide support for research experiences for individuals from diverse backgrounds underrepresented in biomedical research throughout the continuum from high school through the faculty level. NIH expects that these efforts to diversify the workforce will: (1) lead to recruitment of the most talented researchers from all groups; (2) improve the quality of the educational and training environment; (3) balance and broaden perspectives in setting research priorities; (4) improve the ability to recruit subjects from diverse backgrounds into clinical research protocols; and (5) improve the Nation's capacity to address and eliminate health disparities.

NIH developed the [Short-Term Education Program for Underrepresented Persons \(STEP-UP\)](#) Program to expose students from diverse backgrounds underrepresented in biomedical research. The long-term goal has been to increase the pool of underrepresented and disadvantaged students "in the pipeline" who are committed to a career in biomedical, behavioral, clinical, or social science research. To accomplish this goal, the STEP-UP program has provided research education grants to institutions for the support of eligible high school and undergraduate students with research education and training opportunities that will develop both their research capabilities and their interest in pursuing a career in research. The institutions provide administrative support for the STEP-UP program and its student participants throughout the summer research experience.

The [Minority Health and Health Disparities International Research Training \(MHIRT\) Program](#) supports the ability of health professions programs at U.S. academic institutions to offer short-term international training opportunities in health disparities research to undergraduate and graduate students who are from health disparity populations and/or groups underrepresented in the research enterprise. By developing a cadre of researchers who better understand health disparities issues from a global perspective, MHIRT contributes to the eventual elimination of health disparities in the United States. In 2009, the MHIRT program made awards to 22 academic institutions, with grantees traveling to work with international investigators in 41 countries.

The [Minority Institution/Cancer Center Partnership \(MI/CCP\) Program](#) enables minority-serving institutions (MSIs) and NCI-designated Cancer Centers to train scientists from diverse backgrounds in cancer research and to effectively deliver cancer advances to racially and ethnically diverse communities. The program is designed to facilitate planning and implementation of focused partnerships in cancer-related research, training, career development, education, and/or outreach. These partnerships foster and support intensive collaborations to develop stronger cancer programs aimed at understanding the reasons behind significant cancer health disparities among racial/ethnic minorities and socioeconomically disadvantaged populations. The [Continuing Umbrella of Research Experiences \(CURE\) Program](#) offers funding opportunities to support training and career development for students, researchers, and junior investigators using research supplements, predoctoral fellowships, and career development awards. The CURE program promotes unique training and career development opportunities to enhance diversity in cancer and cancer health

disparities research. With a focus on broadening the cadre of investigators from diverse backgrounds engaging in cancer research, the CURE program identifies promising candidates from high school to junior investigator levels and provides them with a continuum of competitive funding opportunities.

The Minority Institution/Cancer Center Partnership program enables minority-serving institutions and NCI-designated Cancer Centers to train scientists from diverse backgrounds in cancer research and to effectively deliver cancer advances to diverse health disparity communities.

The Loan Repayment Programs also help to enhance the diversity of the Nation's biomedical research workforce by alleviating financial barriers for students from diverse backgrounds, including racial/ethnic minority and other scientists from health disparity populations, particularly those pursuing research careers focused on health disparities. The [Loan Repayment Program for Health Disparities Research](#) encourages qualified health professionals to pursue biomedical, clinical, behavioral, and health services research careers. At least 50 percent of the awards are required by law to go to participants from health disparity populations. The [Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds](#) works to increase the participation of eligible individuals in clinical research. In 2009, NCMHD made awards to 314 individuals.

Research Capacity

Another important facet of the NIH mission to reduce and ultimately eliminate health disparities in the United States is the ongoing effort to increase and build the capacity of academic institutions to conduct health disparities research. A number of NIH programs expand training opportunities, foster career development, and increase funding for health disparities research. Projects provide resources to recruit, retain, and provide career development to scientists from diverse health disparity populations, and to expand the pool of investigators eligible to pursue health disparities research.

For example, the [Research Centers in Minority Institutions \(RCMI\) Program](#), which began in 1985 in response to congressional report language, provides a variety of awards to minority-serving institutions to improve research capacity and reduce health disparities. Funds are used to acquire advanced instrumentation, renovate laboratories, and improve research infrastructure, as well as to enhance faculty development and support pilot projects and core facilities. Recently, some RCMI centers have established connections with nearby consortium members of the Clinical and Translational Science Award (CTSA) institutions, enhancing the research capacity at both RCMI centers and CTSA institutions. For example, such collaborations have been established between Emory University and Morehouse School of Medicine (Atlanta), Vanderbilt University and Meharry Medical College (Nashville), and Weill Cornell Medical College and Hunter College (New York) (also see the section on *Clinical and Translational Research* in Chapter 3).

The Research Infrastructure in Minority Institutions (RIMI) program (which will be replaced by the Building Research Infrastructure and Capacity [BRIC] program in FY 2010) directly addresses the need to strengthen the research environment at academic institutions with unique missions and a demonstrated commitment to the needs of health disparity populations, including small junior colleges, tribal colleges and universities (TCUs), and other schools that only offer associate's, bachelor's, and/or master's degrees.

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master's degrees. Grant support helps: to develop or expand existing capacities for research programs (both institutional and individual investigator-driven) that address health disparities; to establish developmental training programs for faculty and students; and to develop collaborations with larger, more research-intensive universities.

The [NCMHD Research Endowment Program](#) is a unique congressionally mandated (Pub. L. No. 106-525) initiative that promotes minority health and health disparities research capacity-building at eligible academic institutions by providing grant funds that are applied directly to an institution's endowment. The interest on that investment must be used to acquire and upgrade equipment and information technology; recruit diverse faculty and develop courses related to minority health and health disparities; and enhance the recruitment and retention of students from diverse backgrounds, including racial/ethnic minority and other students from health disparity populations who are underrepresented in the scientific workforce.

The [Institutional Development Award \(IDeA\) Program](#) improves the competitiveness of investigators in 23 states and Puerto Rico with historically low NIH funding by supporting multidisciplinary centers and statewide collaborative partnerships that increase institutions' capacities to conduct cutting-edge biomedical research. Research supported through this program helps to reduce health disparities in racial/ethnic minority populations, including American Indians, Alaska Natives, Hispanics, Native Hawaiians, and other Pacific Islanders within IDeA states. IDeA has been particularly supportive of efforts to increase connectivity, bandwidth, and access to high-performance computational resources through IDeANet, an Internet-based network providing connectivity for high-bandwidth science applications. For example, cyber infrastructure in six northwestern states (Alaska, Hawaii, Idaho, Montana, Nevada, and Wyoming) has been improved dramatically by the [Lariat Networking Project](#). Five other IDeA states (Delaware, Maine, New Hampshire, Rhode Island, and Vermont) recently formed the [North East Cyberinfrastructure Consortium](#). Ultimately, the IDeANet initiative will enable all institutions in the IDeA program to engage in national and international collaborations.

Conclusion

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 of all Americans, and research remains a fundamental aspect of the national strategy to meet this challenge. NIH will continue to support and conduct a broad range of biomedical and behavioral research focused on relevant diseases and conditions occurring with increased frequency or severity or with worse outcomes in racial/ethnic minorities, rural populations, groups with low income, and other health disparities populations. By accelerating the translation of scientific advances into clinical practice and implementing sound health promotion interventions in communities most affected by health disparities, NIH hopes to eliminate health disparities in affected communities and realize the vision of a world where all will have the opportunity to lead long, healthy, and productive lives.

Notable Examples of NIH Activity

Key

E = Supported through **E**xtramural research

I = Supported through **I**ntramural research

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

COE = Supported via congressionally mandated **C**enter **o**f **E**xcellence program

GPRA Goal = **G**overnment **P**erformance and **R**esults **A**ct

ARRA = **A**merican **R**ecovery and **R**einvestment **A**ct

IC acronyms in **bold** face indicate lead IC(s).

Basic, Clinical, and Translational Research

Compliance with the NIH Policy on the Inclusion of Women and Minorities as Subjects

in Clinical Research: NIH works to ensure compliance with the NIH Policy for the Inclusion of Women and Minorities as Subjects in Clinical Research by convening a trans-NIH committee that addresses consistency in inclusion policy implementation and investigator reporting of population data. Over the past 2 years, NIH has focused on analyzing and streamlining the data reporting process, reemphasizing the vital role of NIH staff to monitor adherence of the NIH Inclusion policy and management of grants, contracts, and cooperative agreements that involve human subjects research. The role of peer reviewers and investigators in meeting policy requirements continues to be stressed. NIH compiled the annual aggregate comprehensive reports: *Monitoring Adherence to the NIH Policy on the Inclusion of Women and Minorities as Subjects in Clinical Research* and the *2009 Biennial Report Certifying IC Compliance with the Inclusion Guidelines* based upon IC Advisory Council reviews, as required by statute.

- For more information, see <http://orwh.od.nih.gov/inclusion.html>
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E/I) (**ORWH**, OER, OIR)

Translating Basic Science into New and Better Treatment for HIV/AIDS:

The HIV/AIDS pandemic has proven to be one of the most significant challenges faced by the biomedical research community. In the United States this devastating illness heavily has burdened racial and ethnic minority populations and other medically underserved populations. NIH has made a significant investment in research to elucidate basic HIV biology. The Center for AIDS Health Disparities Research (CAHDR) is engaged in research to understand the biological basis for HIV/AIDS disparities among racial and ethnic groups. The overall mission is to develop interventions that will help eliminate the disparities, and ultimately benefit all people at risk of HIV/AIDS. Recent basic and translational research in the CAHDR has focused on understanding how the virus exploits certain cellular proteins for its own purposes and how it hijacks cellular machinery. A particular focus of the research has examined the role of cholesterol in HIV biology. Cholesterol is critical to many cellular processes, including the fusion of cells to one another. Fusion is how HIV enters cells, and CAHDR research has shown that cholesterol controls the fusion of HIV to cells, and also controls the production of new HIV particles by infected cells. Findings also have revealed that HIV emerges from areas of the cell membrane rich in cholesterol, causing the virus itself to be rich in cholesterol. CAHDR investigators also have demonstrated that the sugar betacyclodextrin (BCD) can inactivate HIV and also make cells resistant to infection by removing cholesterol. This sugar, in one form or another, is used widely in consumer products such as food and cosmetics, and also is used by major pharmaceutical companies as a carrier for drugs. As such, BCD has a proven and extensive safety record of use in humans and has major potential as a prophylactic against HIV to be used in the form of a vaginal microbicide (a gel or cream that would protect women against infection). The most recent work has found that a protein controlling the activation of HIV genes is itself controlled by the levels of cholesterol in a cell. This means that cholesterol directly influences the genetic replication of HIV. The NIH-funded Meharry Translational Research Center will continue to investigate HIV's varied reliance on cholesterol for survival and its implications for developing potential new treatments for HIV

infections and for treating AIDS patients with lipid imbalances.

- (E) (NCRR)

Centers of Research Translation (CORT): The NIH CORTs are designed to bring together basic and clinical research to translate basic discoveries into new drugs, treatments, and diagnostics. Each CORT encompasses at least three projects, including one clinical and one basic research study. The centers are:

- The Center for Translating Molecular Signal Pathways to Orthopaedic Trauma Care studies the biological basis of fracture healing and the efficacy of a potential new treatment, teriparatide, an injectable form of human parathyroid hormone that stimulates new bone formation.
 - The Center for Lupus Research investigates the role of different cell types in the origin and development of lupus, markers of disease activity and severity, and new targets for treatment.
 - The Center for X-Linked Hypophosphatemic Rickets Research focuses on the various molecular contributors to this genetic form of rickets, and works toward developing new treatments.
 - The Center for Research Translation in Scleroderma is studying the molecular basis of scleroderma to understand its underlying causes, using functional genomics and gene networks.
 - The Center for Genetic Dissection of Systemic Lupus Erythematosus (lupus) studies mouse models of lupus to identify the genetic background of developmental stages of the disease.
 - The Center for New Approaches to Assess and Forestall Osteoarthritis in Injured Joints is developing new methods of forestalling post-traumatic osteoarthritis (PTOA).
 - The Center for Psoriasis Research Translation uses a Phase I mechanistic, safety, and preliminary efficacy study to test a novel photodynamic therapy for psoriasis.
- For more information, see http://www.niams.nih.gov/News_and_Events/Press_Releases/2006/11_08.asp
 - For more information, see http://www.niams.nih.gov/News_and_Events/Announcements/2007/corts.asp
 - This example also appears in Chapter 2: *Autoimmune Diseases* and Chapter 3: *Clinical and Translational Research*
 - (E) (NIAMS)

Behavioral and Social Science Research on Understanding and Reducing Health

Disparities: NIH, with CDC, issued two program announcements with review to fund behavioral and social sciences research on health disparities. These announcements called for research to improve and elaborate explanations and understandings of the causes for health disparities. In so doing, the announcements stressed the explicit employment of concepts and models from the behavioral and social sciences to guide basic and applied research by focusing on three action areas: Public Policy, Health Care, and Disease/Disability Prevention. They emphasized basic research on the behavioral and social (acting with or through biological) pathways that give rise to disparities in health and applied or translational research on the development, testing, and delivery of interventions to reduce disparities. They encouraged a multilevel analytic framework in investigating public health issues and their interactions (e.g., multiple morbidities rather than single illnesses), as well as attention to risk factors or causal processes common to various health conditions (e.g., smoking, diet, exercise, and access to health care). To date about 30 projects have been funded. In 2009, the Economic and Social Research Council of the United Kingdom and NIH issued a joint call for applications and funded six additional research grants involving collaborations between American and British research teams.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PAR-07-379.html>
- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PAR-07-380.html>
- For more information, see <http://esrcsocietytoday.ac.uk/ESRCInfoCentre/opportunities/international/esrc-nih.aspx>
- (E) (OBSSR, NCI, NIA, NIAAA, NICHD, NIDDK, NINR)

Medical Technologies that Reduce Health Disparities: Appropriate medical technologies should be effective, affordable, culturally acceptable, and deliverable to those who need them. NIH is funding a research initiative to support the development of appropriate medical technologies for underserved settings. To ensure that the technology is appropriate, applications must involve interactions with underserved populations and/or collaborations with clinics in an underserved community.

- For more information, see <http://grants.nih.gov/grants/guide/rfa-files/RFA-EB-09-001.html>
- This example also appears in Chapter 3: *Technology Development*
- (E) (NIBIB, NCMHD, NCCR, NIMH)

Cancer Health Disparities Research Programs and Initiatives: NIH has expanded research on the basic biologic factors of cancer disparities to provide a foundation for minimizing risk, identifying targets, developing preventive and therapeutic interventions, and understanding how genetic susceptibility may be influenced by social, economic, race/ethnicity, and geographic factors. Thus, the research programs involve multidisciplinary teams, which contribute to understanding the etiology of cancer and build prevention and intervention evidence-based models to eliminate cancer disparities. Several programs at NIH address disparities along the cancer continuum from prevention to survival.

- The trans-disciplinary Geographic Management Program (GMaP) pilot initiative builds regional networks to support research, training, and infrastructure to develop state-of-the-art networks/centers to ensure a continuous supply of high-quality human biospecimens from multi-ethnic communities.
 - The Community Networks Program engages communities experiencing cancer disparities to design, test, and evaluate evidence-based strategies to address critical needs, such as access to screening, mentoring, and training; policy development; and community outreach and education.
 - The Patient Navigation Research Program builds partnerships to ensure that racial/ethnic minorities and underserved populations with abnormal cancer screening results receive appropriate care.
 - The Community Clinical Oncology Program is a network for conducting cancer prevention and treatment clinical trials by connecting academic centers with community physicians.
 - The NIH Centers for Population Health and Health Disparities catalyze transdisciplinary research to improve the understanding of complex interactions of biological, social, cultural, environmental, and behavioral factors that contribute to health inequities, and to develop and implement novel intervention strategies that are multilevel and multifactorial.
 - The Tobacco Research Network on Disparities' mission is to understand and address tobacco-related disparities by advancing the science, translating that scientific knowledge into practice, and informing public policy.
 - The Centers of Excellence in Cancer Communication Research continue to use best practices in communication science to extend the reach of biomedical benefits equitably throughout the population.
- For more information, see <http://crchd.cancer.gov/>
 - For more information, see <http://crchd.cancer.gov/cnp/background.html>

- For more information, see <http://crchd.cancer.gov/png/pnpr-index.html>
- For more information, see <http://cancercontrol.cancer.gov/populationhealthcenters/cphhd/index.html>
- This example also appears in Chapter 2: *Cancer*, Chapter 3: *Molecular Biology and Basic Research* and Chapter 3: *Clinical and Translational Research*
- (E) (NCI)

Lupus: There have been significant advances in identifying disease risk genes for systemic lupus erythematosus (lupus) in recent years. Genome-wide association, linkage analysis, and direct sequencing have revealed genetic variations in lupus patients for molecules involved in immune mechanisms and regulation, inflammation, and vascular cell activities. The disease affects women disproportionately, with female lupus patients outnumbering males nine to one. African American women are three times as likely to get lupus as Caucasian women, and it also is common more in Hispanic, Asian, and American Indian women. These results are being replicated in distinct racial and ethnic populations. Long-term NIH support of disease registries and repositories of biological samples have been essential to successful projects. Another critical factor in these and future studies is the collaboration between U.S. and European researchers, supported by government agencies, private foundations, and industry. The numerous genes uncovered in these studies reflect the complex expression of lupus, which varies from patient to patient. For example, a variant in an immune regulatory gene specifically is associated with severe forms of lupus that include kidney disease, but not skin manifestations. Methods to analyze patients' blood samples are being developed to group disease-specific variations in gene expression according to pathogenic mechanisms. This system may be used to predict flares of lupus activity in the future and guide individualized treatment. Lupus risk genes also have been discovered on the X chromosome and reproduced in animal models of the disease. These important findings shed light on the female predominance of lupus.

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- Nath SK, et al. *Nat Genet* 2008;40(2):152-4. PMID: 18204448.
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- Taylor KE, et al. *PLoS Genet* 2008;4(5):e1000084. PMID: 18516230. PMID: PMC2377340.
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- Jacob CO, et al. *Proc Natl Acad Sci U S A* 2009;106(15):6256-61. PMID: 19329491. PMID: PMC2669395.
- This example also appears in Chapter 2: *Autoimmune Diseases*, Chapter 3: *Genomics*, Chapter 3: *Molecular Biology and Basic Research* and Chapter 3: *Clinical and Translational Research*
- (E/I) (NIAMS, NCI, NCRR, NHLBI, NIAID, NIDCR, NINDS)

Diabetes Prevention Program Outcomes Study (DPPOS) and Translational

Research: The landmark NIH Diabetes Prevention Program (DPP) clinical trial showed that lifestyle change or treatment with the drug metformin significantly delayed development of type 2 diabetes in people at high risk. This finding was true across all participating ethnic groups and for both men and

women. The DPPOS is a long-term follow-up study of the DPP participants that is determining the durability of the interventions in preventing or delaying type 2 diabetes, and how the interventions affect the development of cardiovascular disease and other complications of diabetes. The DPP group was highly diverse (45 percent from minority ethnic and racial groups), and DPPOS will compare outcomes for women and men, and by age and ethnicity. Renewed in FY 2009 for a second 5-year phase, the DPPOS will enable researchers to better determine the lasting benefits of the interventions to diabetes prevention and/or the delay of onset. In addition, NIH is pursuing translational research efforts to develop more cost-effective methods of achieving the lifestyle change that delayed or prevented diabetes in the DPP, and better methods to identify those with prediabetes. For example, one translational effort is using the YMCA to deliver a DPP lifestyle intervention; data from a recent pilot study suggest that using the YMCA may be a low-cost way to deliver a lifestyle intervention to large numbers of people in the United States. Many of these translational research studies focus on minority populations disproportionately burdened by type 2 diabetes and by obesity, a significant risk factor for type 2 diabetes.

- For more information, see <http://www.bsc.gwu.edu/dpp/protocol.htmlvdoc>
- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PAR-09-176.html>
- 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, CDC, IHS, NEI, NHLBI, NIA, NICHD, NINR, OBSSR, ORWH)

Look AHEAD (Action for Health in Diabetes): This NIH-led, multicenter, randomized clinical trial is examining the long-term health effects of an intensive lifestyle intervention (ILI) designed to achieve and maintain weight loss through decreased caloric intake and increased physical activity. The study enrolled more than 5,100 overweight or obese adults with type 2 diabetes. Results from the first year of the study showed that participants in the ILI group achieved clinically significant weight loss; this was the case across all subgroups of the ethnically and demographically diverse study population. In addition, this weight loss was associated with an increase in "health-related quality of life" and improved cardiovascular fitness, blood pressure, cholesterol, and blood glucose, as compared to a control group receiving diabetes support and education. As another major point for health outcome measurement, the study recently completed 4 years of intervention and follow-up. In the coming years, continued follow-up of the Look AHEAD participants will show whether the ILI can reduce the incidence of heart attack and stroke and improve other health-related outcomes in this population. These findings will have important implications for treating type 2 diabetes.

- For more information, see <http://www2.niddk.nih.gov/Research/ClinicalResearch/ClinicalTrials/Patients/ClinicalResearch/lookahead.htm>
- 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)

Genetics of Diabetes: Diabetes is a common, potentially deadly and debilitating chronic disease that poses an enormous health care burden. Both of the most common forms of diabetes, type 1 and type 2, are caused by an intersection of genetic and environmental risk factors. Although genetic effects on developing diabetes are profound, they are not simple, as there are many genes that influence the likelihood of developing type 1 or type 2 diabetes. Further, ethnicity impacts both genetic

and environmental risk factors. To learn more about diabetes genetics, particularly through new genomic technologies, NIH supports the Type 1 Diabetes Genetics Consortium to study type 1 diabetes, and several major grants to study the genetics of type 2 diabetes. These programs now have identified at least 40 genetic regions linked to type 1 diabetes and at least 38 type 2 diabetes genes. Other studies are refining our understanding of how these genes affect diabetes risk. Many of these projects are geared to collect data from multiple ethnic groups, but a recent initiative sought to advance knowledge of diabetes risk genes in specific racial and ethnic groups disproportionately affected by type 2 diabetes, to understand how different genes affect different populations.

- For more information, see <http://grants.nih.gov/grants/guide/rfa-files/RFA-DK-09-004.html>
- For more information, see <http://www.t1dgc.org>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Genomics*
- (E) (NIDDK, NHGRI, NIAID, NICHD)

Genetics of Chronic Kidney Disease: Researchers recently have made progress in uncovering the role of genetics in chronic kidney disease (CKD) arising from various causes.

Scientists recently have identified a genetic region that is strongly associated with CKD in African Americans that arises as a consequence of conditions other than diabetes, such as high blood pressure and HIV-associated kidney disease. Several variants associated with the *MYH9* gene were identified as major contributors to excess risk of this kind of CKD among African Americans. This finding suggests that CKD may proceed along different paths depending on whether diabetes or another condition is the underlying disorder. The Consortium for Radiologic Imaging Studies of PKD (CRISP) was established to study progression of an inherited form of kidney disease, polycystic kidney disease (PKD). Phase I of the study demonstrated that magnetic resonance imaging accurately could track structural changes in the kidneys; Phase II showed that patients with mutations in the *PKD1* gene have more cysts and larger kidneys than patients with *PKD2* mutations. A planned third phase of CRISP will provide critical information about the validity of changes in kidney volume as a surrogate marker for loss of kidney function. NIH also has launched a study to identify and validate biomarkers and risk assessment tools for kidney function, injury, and disease progression in patients with CKD, to predict risk, aid early diagnosis, and assess disease progression.

- Kopp JB, et al. *Nat Genet* 2008;40(10):1175-84. PMID: 18794856.
- Kao WHL, et al. *Nat Genet* 2008;40(10):1185-92. PMID: 18794854. PMID: PMC2614692.
- Grantham JJ, et al. *New Engl J Med* 2006;354(20):2122-30. PMID: 16707749.
- Rule AD, et al. *J Am Soc Nephrol* 2006;17(3):854-62. PMID: 16452494.
- For more information, see <http://www.nih.gov/news/health/sep2008/niddk-14.htm>
- For more information, see <http://www.nih.gov/news/pr/may2006/niddk-17.htm>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Genomics*
- (E/I) (NIDDK, AHRQ, NCI, NCRR, NHLBI)

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. Planned recruitment of 4,000 participants is more than three-quarters complete. Scientists are using mobile medical research vehicles to make possible onsite bone density and carotid artery imaging, physical examination and blood sampling, physical and

cardiovascular performance, participant interviews, cognitive testing, and psychophysiological testing. HANDLS also will include studies of other variables, including: nutrition, environment and neighborhood effects, genetic make-up, family history, and access to health care. Participants 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>
- This example also appears in Chapter 2: *Life Stages, Human Development, and Rehabilitation*
- (E) (NIA)

OAR Management and Coordination of Trans-NIH HIV/AIDS Research to Address the AIDS Epidemic in the United States:

Every nine and a half minutes, someone in the United States is infected with HIV. It is estimated that in 2006, 56,300 people were newly infected with the virus. There are large disparities in the prevalence of HIV among different racial and ethnic populations. Black men and women, Hispanic men, and men who have sex with men of all races are impacted disproportionately by HIV. In 2006, blacks accounted for 45 percent of new infections and Hispanics for 17 percent, even though those populations comprised only 13 percent and 15 percent, respectively, of the U.S. population at that time. Moreover, the prevalence rate for black men was six times the rate for white men, and the rate for Hispanic men was more than twice that for white men. OAR leads the trans-NIH planning and coordination efforts in the area of AIDS research in racial and ethnic populations. A section of the annual Trans-NIH Plan for HIV-Related Research is specifically dedicated to research in this area. The Plan, developed in collaboration with scientific experts and community members, serves as a roadmap for the planning of AIDS-related research in this area. OAR also supports a multifaceted initiative to address the U.S. epidemic, particularly in racial and ethnic populations. For example, OAR has launched a new initiative to address the serious and complex AIDS epidemic in U.S. Hispanic populations through community outreach, regional workshops, leadership development, and research collaborations. In addition, OAR, in collaboration with NIAID and the NIH CC, has provided key support for a new trans-NIH initiative on AIDS in the District of Columbia, a city with large black and Hispanic populations and where 3 percent of the population is known to be infected with HIV.

- Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2007. Vol. 19. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2009. Available at www.cdc.gov/hiv/topics/surveillance/resources/reports/. Accessed July 14, 2009.
- Centers for Disease Control and Prevention. HIV Prevalence Estimates—United States, 2006. MMRW. 2008; 57(39):1073-1076. Available at www.cdc.gov/mmwr/preview/mmwrhtml/mm5739a2.htm. Accessed July 14, 2009.
- For more information, see <http://www.oar.nih.gov/strategicplan/fy2010/pdf/Chapter5.pdf>
- For more information, see <http://www.nineandahalfminutes.org>
- This example also appears in Chapter 2: *Infectious Diseases and Biodefense*
- (O) (OAR)

Microbiome of the Lung and Respiratory Tract in HIV: Research grant applications were solicited in 2009 for studies to characterize the lung and respiratory tract microbiota in HIV-infected individuals and matched HIV-uninfected controls, using molecular and high-throughput techniques to identify bacteria and other organisms, including viruses, cell-wall deficient organisms, protozoa, and

fungi. The characteristics and mix of organisms populating the respiratory tract, coupled with the state of local respiratory defenses, are key factors in determining whether a person remains healthy or develops infection. HIV-infected individuals are at very high risk of developing pneumonias caused by pathogenic and opportunistic microorganisms. These respiratory infections frequently cause morbidity, and they often are life-threatening. They also may increase the rate of replication of HIV, accelerating the course of HIV disease. HIV-infected individuals often experience decreased lung function following pneumonia which is not observed in normal, HIV-uninfected populations. Furthermore, lung infections and microbial colonization are suspected in the etiology of HIV-associated emphysema and pulmonary hypertension. Lung infections also may play a role in inducing the immune reconstitution syndrome seen in some HIV-infected patients following initiation of multidrug antiretroviral regimens. Knowledge of the role of the lung microbiome in preserving health or causing disease and the divergent effects observed in HIV-infected vs. uninfected individuals may lead to the identification of predictors of disease progression and therapeutic targets for translation into better preventive and treatment strategies.

- For more information, see <http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-09-006.html>
- This example also appears in Chapter 2: *Infectious Diseases and Biodefense*
- (E) (NHLBI)

Centers of Excellence Program: The congressionally mandated NCMHD Centers of Excellence Program 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 since its inception created hundreds of unique partnerships with hospitals, tribal groups, health plans, health centers, community- and faith-based organizations, civic and nonprofit health organizations, and local, city, and state governments. The research conducted by NCMHD Centers of Excellence and their community partners is expanding understanding of health disparities through numerous publications in the peer-reviewed scientific literature, press releases, television spots, websites, 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 32 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. NIH supported 49 COEs in FY 2008 and 51 COEs in FY 2009. In May 2009, NIH issued RFA MD-09-007, "Recovery Act Limited Competition: NCMHD Center of Excellence (P20)" to establish COEs having a project period of 2 years compared to the traditional project period of 5 years. It is expected that Recovery Act funds will aid in stimulating the economy and seed the development of emerging research infrastructures capable of generating and supporting innovative partnerships, and creative program and research strategies for advancing minority health, eliminating health disparities, and attracting new funding streams; awards for this competition will be made in FY 2009. Currently funded examples of NCMHD Centers of Excellence program projects include:

- Insulin Resistance and Glucocorticoids
- Parent Diabetes Prevention Trial (STPDPT)
- The Right Question Project-Mental Health II
- Race and Ethnic Disparities in Mental and Cardiovascular Health Disorders: Stress, Self-Regulation of Health Behaviors, and the HPA-Axis
- Using Resistance Training to Reduce Metabolic and Cardiovascular Disease Risk in Obese

Hispanic and African American Youth

- (E) (NCMHD)

Epidemiological/Population Research

The Strong Heart Study: The Strong Heart Study was initiated in 1988 to estimate the morbidity and mortality from cardiovascular disease (CVD) in 3 geographically diverse groups of American Indians and to estimate the levels of CVD risk factors in 4,549 adult men and women aged 45-74 in 3 centers. It evolved into a study of large families after a successful pilot study in each center. The original cohort was examined three times and continues to be followed for morbidity and mortality. The family study currently is completing its second examination and has conducted a linkage study of multiple cardiovascular phenotypes.

- For more information, see <http://strongheart.ouhsc.edu>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems*
- (E) (NHLBI)

The Coronary Artery Risk Development in Young Adults (CARDIA) Study: CARDIA is studying the distribution and evolution of risk factors for cardiovascular disease (CVD) during young adulthood in 5,115 African-American and white men and women who were aged 18-30 years when the study began in 1985. The project has completed 7 examinations of these participants over 20 years. CARDIA has measured standard CVD risk factors at all examinations to permit analyses of secular trends and interrelationships among risk factors. Measures of subclinical CVD, such as coronary artery calcium, carotid intima-media wall thickness, arterial compliance, and left ventricular mass and function also have been assessed. DNA will be analyzed to elucidate how genetic variability and gene-environment interactions may explain differences in the severity and progression of CVD. Major objectives for the upcoming eighth examination include identifying early adulthood antecedents and consequences of obesity, understanding the determinants and trajectories of CVD development in women during the menopausal transition, and further assessing the basis for racial differences in the development and progression of CVD.

- For more information, see <http://www.cardia.dopm.uab.edu>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems*
- (E) (NHLBI)

Genetics of Coronary Artery Disease in Alaska Natives Study: This is a study of large families of Alaska natives (Eskimos) living in Nome and surrounding villages. Recruitment of 1,214 individuals in approximately 40 families has been accomplished. A genome-wide scan of almost 400 microsatellite markers and linkage analyses with cardiovascular disease risk factors and subclinical disease measures were completed recently to search for relevant genes. Phase II is nearing completion and will establish surveillance of the cohort, add four villages that were part of a previous study following a similar protocol, conduct a second examination on the cohort, and pursue significant linkage findings.

- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems*

- (E) (NHLBI)

The Multi-Ethnic Study of Atherosclerosis: The Multi-Ethnic Study of Atherosclerosis (MESA) is a multicenter epidemiological study of cardiovascular disease (CVD) in 6,914 men and women from 4 ethnic groups—white, African-American, Hispanic, and Chinese—who have been followed for almost 10 years to identify predictors of progression of subclinical CVD. The study originally was funded from 1999 to 2008 and subsequently renewed through 2015. It has measured and compared the predictive value of chest computed tomography, cardiac magnetic resonance imaging, carotid ultrasound, arterial compliance, endothelial function, biochemical markers, and genetic and environmental factors for the development of CVD. MESA has major ongoing ancillary studies in the areas of air pollution (funded by the EPA), chronic lung disease, and genetics. MESA SHARe (SNP Health Association Resource) will combine genome-wide scans with detailed phenotypic information and share these data with the scientific community for genome-wide association analyses.

- For more information, see <http://mesa-nhlbi.org>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems*, Chapter 3: *Epidemiological and Longitudinal Studies* and Chapter 3: *Genomics*
- (E) (NHLBI, NEI)

Reducing Disparities in Stroke: NIH actively is 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 stroke risk factor prevalence and stroke incidence and mortality. Recruitment of the main REGARDS cohort was completed at the end of 2007 with 30,229 participants (41 percent African American and 59 percent white, 55 percent female and 45 percent male), and includes participants from 1,833 of the 3,111 counties (59 percent) in the 48 contiguous United States. The group already has published a number of important findings that partially explain why African Americans and residents of the southeastern "Stroke Belt" have higher risk of dying from stroke, and also findings documenting the consequences of not reporting stroke symptoms, including poor health outcomes and death. NIH also has established an acute stroke research and care center at the Washington Hospital Center (WHC), 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 tPA use among minorities. The program directly addresses GPRA goal: *By 2018, identify culturally appropriate, effective stroke prevention/intervention programs in minority communities.*

- Howard G, et al. *Prev Med* 2009;49(2-3):129-32. PMID: 19285103. PMID: PMC2778033.
- Cushman M, et al. *Ann Neurol* 2008;64(5):507-13. PMID: 19067365. PMID: PMC2802965.
- Howard G, et al. *Stroke* 2007;38(9):2446-52. PMID: 17673720.
- Wadley, G, et al. *Stroke* 2007;38:1143-1147. PMID: 17322077.
- 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) (GPRA)

The Sister Study: Environmental Risk Factors for Breast Cancer: The NIH Sister Study prospectively examines environmental and familial risk factors for breast cancer and other diseases in a cohort of 50,000 sisters of women who have had breast cancer. The frequency of relevant genes and shared risk factors is greater among sisters, increasing the ability of the study to detect risks. Researchers will collect data on potential risk factors and current health status, and will collect and bank blood, urine, and environmental samples for future use in studies of women who develop breast cancer or other diseases compared with those who do not. Analysis of new cases will assess the separate and combined effects of environmental exposures and genetic variations that affect estrogen metabolism, DNA repair, and response to specific environmental exposures. Future analyses will focus on known and potential risk factors like smoking, occupational exposures, alcohol, diet and obesity, and include analysis of phthalates, phytoestrogens, metals, insulin, growth factors, vitamins and nutrients, and genes in blood and urine. The study also allows investigators to examine a wide range of health outcomes of relevance to women, and to create a framework from which to test new hypotheses as they emerge. In addition to its focus on genetic and environmental causes of breast cancer, the prospective Sister Study tracks changes in health status over time. Among the chronic diseases currently studied are uterine fibroids and endometriosis, rheumatoid arthritis and other autoimmune diseases, thyroid disease, asthma, and cardiovascular diseases. As the cohort ages, the Sister Study will address aging-related health outcomes including osteoporosis, Parkinson's disease, and age-related cognitive decline.

- For more information, see <http://www.niehs.nih.gov/research/atniehs/labs/epi/studies/sister/index.cfm>
- This example also appears in Chapter 2: *Cancer*, Chapter 2: *Chronic Diseases and Organ Systems*, Chapter 2: *Life Stages, Human Development, and Rehabilitation* and Chapter 3: *Epidemiological and Longitudinal Studies*
- (E/I) (NIEHS, NCMHD)

Advances in Minority Mental Health Research: Results from NIH's Collaborative Psychiatric Epidemiology Surveys (CPES) have continued to shed light on the risk, prevalence, and outcomes associated with mental disorders in minority populations. Two CPES surveys, the National Latino and Asian American Study (NLAAS), and the National Survey of American Life (NSAL), are large, nationally representative epidemiologic surveys that focus, respectively, on the mental health epidemiology of Latinos and Asians, and African Americans. Examples of important research that has emerged from the CPES include an FY 2009 study from the NSAL that found that African American teens, especially girls, are at increased risk for suicide attempts, even if they have not been diagnosed with a mental disorder. The study's findings may be used to improve clinicians' screenings for suicidal behavior among adolescent African Americans. Additionally, an FY 2009 study using data from the NLAAS and the National Co-morbidity Survey Replication found that previous research showing native-born Latinos to be at higher risk for mental disorders than nonnative-born Latinos may not be true across all Latino subgroups. NLAAS researchers found that this widely reported phenomenon (the "immigrant paradox") was true in some subgroups, but it did not hold in others (e.g., among Puerto Ricans). The results emphasize the heterogeneity of the Latino population and suggest the importance of addressing this population's subgroups in future research.

- Joe S, et al. *J Am Acad Child Adolesc Psychiatry* 2009;48(3):271-82. PMID: 19182692. PMID: PMC2760075.
- Alegria M, et al. *Am J Psychiatry* 2008;165(3):359-69. PMID: 18245178. PMID: PMC2712949.

- For more information, see <http://www.nimh.nih.gov/science-news/2009/black-teens-especially-girls-at-high-risk-for-suicide-attempts.shtml>
- This example also appears in Chapter 3: *Epidemiological and Longitudinal Studies*
- (E) (NIMH)

A Look at Drug Abuse Trends: Local to International: Two major systems of data collection are helping to identify substance abuse trends locally, nationally, and internationally: Monitoring the Future Survey (MTF) and the Community Epidemiology Work Group (CEWG). Both 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 also have been 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 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. CEWG findings reported in 2008 and 2009 show decreases in methamphetamine indicators (e.g., treatment admissions), suggesting that the problems that had escalated in the first half of the decade may have stabilized or declined. Development of a Latin American Epidemiology Network is underway. NIH also has 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: *Epidemiological and Longitudinal Studies* and Chapter 3: *Disease Registries, Databases, and Biomedical Information Systems*
- (E) (NIDA)

Fetal Alcohol Effects: The developing embryo and fetus is very vulnerable to the adverse effects of alcohol. Since Fetal Alcohol Syndrome was first recognized around 1970, NIH has supported research on outreach to pregnant women for identification and intervention of risky drinking; research to enhance our ability for early identification of and interventions with prenatal alcohol-affected children; research exploring nutritional and pharmacological agents that could lessen alcohol's adverse effects on the developing embryo/fetus; and research on how alcohol disrupts normal embryonic and fetal development. For example, a recent study with rats showed that choline, an essential nutrient, was found to effectively reduce the severity of some fetal alcohol effects, even when administered after the ethanol insult was complete. NIH also is investing in a large-scale prospective study looking at prenatal alcohol exposure along with other maternal risk factors in adverse pregnancy outcomes. Following a 3-year feasibility study, NIH established the Prenatal Alcohol, Sudden Infant Death Syndrome, and Stillbirth (PASS) Research Network, a multidisciplinary consortium to determine the role of prenatal alcohol exposure and other maternal risk factors in the incidence and etiology of sudden infant death syndrome (SIDS), stillbirth, and fetal alcohol syndrome, all of which are devastating pregnancy outcomes. The PASS study prospectively will follow 12,000 pregnant, high-risk, American Indian and South African women and their infants until the infants are 12 months old.

Maternal, fetal, and infant measures and tissues will be obtained for analysis.

- For more information, see <http://www.nichd.nih.gov/research/supported/pass.cfm>
- This example also appears in Chapter 2: *Life Stages, Human Development, and Rehabilitation* and Chapter 3: *Epidemiological and Longitudinal Studies*
- (E) (NIAAA, NICHD)

Improving the Lives of Asthmatic Children in the Inner City: The NIH Inner-City Asthma Consortium (ICAC) of 10 academic clinical centers, launched in 2002, evaluates the safety and efficacy of promising immune-based therapies to reduce asthma severity and prevent disease onset in inner-city children. The Consortium also pursues studies to understand mechanisms underlying the onset and progression of asthma and research to develop diagnostic and prognostic biomarkers. An ICAC longitudinal birth cohort study involving 500 inner-city children is investigating the immunologic causes of the development of recurrent wheezing, which can be indicative of asthma in children under age 3. ICAC has extended the study to follow all participant children to age 7, when the diagnosis of asthma can be definitive. Researchers hope to identify immunologic characteristics that will predict the development and severity of asthma at a later age. ICAC researchers are conducting two clinical trials to determine the safety, dosing levels, and biologic activity of a potential new allergy immunotherapy for cockroach allergen, which ICAC studies previously found to be a major determinant of asthma severity among inner-city children. Finally, an ICAC clinical trial assessed the benefit of using exhaled nitric oxide (NO) as a marker for asthma management. Although the study reinforced the importance of the NIH asthma guidelines for disease control, it did not find that measuring exhaled NO provided any additional clinical benefit.

- Szeffler SJ, et al. *Lancet* 2008;372(9643):1065-72. PMID: 18805335. PMCID: PMC2610850.
- For more information, see <http://www3.niaid.nih.gov/topics/asthma/research/researchActivities.htm>
- This example also appears in Chapter 2: *Chronic Diseases and Organ Systems* and Chapter 3: *Clinical and Translational Research*
- (E) (NIAID)

The Hispanic Community Health Study: In October 2006, NIH began the largest long-term epidemiological study of health and disease ever conducted in people of Hispanic/Latino heritage living in the United States. The study includes 16,000 participants of diverse Hispanic/Latino background, including Mexican, Cuban, Puerto Rican, and Central/South American. It is designed to identify factors that render these groups either susceptible to or protected from heart disease, stroke, asthma, chronic obstructive pulmonary disease, sleep disorders, dental disease, hearing loss, diabetes, kidney and liver disease, cognitive impairment, and other chronic conditions. Recruitment started in March 2008 in four cities. Variables such as height, weight, and other body measurements; blood pressure; blood lipids and glucose levels; diet; physical activity; smoking; acculturation; socioeconomic status; psychosocial factors; occupational history and exposure; access to and use of health care services; and use of medications and dietary supplements currently are being assessed.

- For more information, see <http://www.csc.unc.edu/hchs>
- 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, ODP/ODS)

Outreach

Minority Health Information Access: An NIH outreach goal is to reduce health disparities among African American, Hispanic, and Native American populations by using a variety of approaches to promote access to and use of health information among diverse communities. The Historically Black Colleges and Universities (HBCU) ACCESS Project, developed in partnership with the United Negro College Fund Special Programs, provides technical assistance, training, and funding for locally developed projects incorporating the use of NIH information resources in HBCU campuses and communities. The Environmental Health Information Partnership enhances the capacity of 20 academic institutions that provide health-related services and information to health disparity populations by supporting their efforts to reduce health disparities through the access and use of environmental health information. Projects to increase the knowledge of Native Hawaiian community members about health information were completed at the community of Miloli'i and Waimanolo Health Center. At Cankdeska Cinkana Tribal College, Spirit Lake Nation, a health-related education program was developed along with tribal library improvements. Specialized websites, developed and expanded in partnership with community representatives, collect and organize information for specific populations such as Asian Americans, American Indians, and peoples of the Arctic. In the Lower Rio Grande Valley, the VIVA! Peer Tutors program at a magnet health high school is an award-winning effort to involve high school students in teaching their peers about online health information. The project has been extended to other schools and expanded to include promotion of health careers.

- 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)

MedlinePlus and MedlinePlus En Espanol: MedlinePlus and the Spanish language MedlinePlus En Espanol provide access to high-quality consumer health information on more than 800 diseases and conditions, with authoritative information from NIH, other government agencies, and health-related organizations. Enhancements in FYs 2008-2009 included improved search capabilities and addition of summary information. Content also was expanded to include information in more than 40 languages, addressing the growing needs of non-English-speaking patients. Go Local links from MedlinePlus, developed in partnership with libraries across the country, enable users to find relevant health services in local geographic areas. The number of Go Local sites increased to 34 in FY 2009, covering 46 percent of the U.S. population. The *NIH MedlinePlus Magazine* transmits the latest useful research findings in lay language, with feature stories on topics such as colorectal cancer, post-traumatic stress disorder, and childhood diseases. More than 600,000 copies of the magazine were distributed free to physician offices in FY 2009, up from 50,000 in FY 2006. In addition, a Spanish language edition, *Salud!*, was launched in FY 2009, as were online versions of both English and Spanish language magazines.

- For more information, see <http://www.medlineplus.gov>
- For more information, see <http://medlineplus.gov/spanish>
- This example also appears in Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*

- (I) (NLM)

National Network of Libraries of Medicine (NN/LM): With more than 5,800 full and affiliate members representing academic health sciences libraries, hospital libraries, public libraries, and community-based organizations, the NN/LM plays a pivotal role in NIH's outreach programs to reduce health disparities and improve health information literacy. In FYs 2008-2009, NIH funded more than 400 community-based projects to enhance access to health information for health disparity and other medically underserved populations, building upon longstanding relationships with institutions providing health-related services and information to health disparity populations and developing many new relationships with schools, churches, public health departments, and others interested in improving health literacy and information access. Projects took place in rural and inner city communities and special populations in 35 states and the District of Columbia. The NN/LM also is a key player in the MedlinePlus "Go Local" service, which provides information about local community services to complement the nationally applicable health information in MedlinePlus. Go Local coverage reached 46 percent of the U.S. population in FYs 2008-2009. With an excellent track record of providing access to health information for clinicians and patients displaced by disasters, the NN/LM is the backbone of NIH's strategy to promote more effective use of libraries and librarians in local, State, and national disaster preparedness and response efforts. In FY 2008, a major initiative was the development of a national NN/LM Emergency Preparedness Plan to ensure backup health library services in the aftermath of a disaster and establish librarians as key community resources in disaster planning and response.

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

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 underserved and rural kindergarten to grade 12 (K-12) students, and 2) engaging and educating the general public on 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. In FY 2008, SEPA supported 68 projects, of which 50 targeted middle- and high-school students and 18 were based in science centers and museums.

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

Peer Tutor High School Program in the Lower Rio Grande Valley: The Peer Tutor Program is a school- and community-based collaborative outreach program that trains high school peer tutors in

NIH online health information resources, and then empowers these students in turn to train their peers and to go into the local communities to train the citizenry. The majority of the peer tutors and students in participating schools are Hispanic. In place for more than 5 years, the program has trained more than 50 peer tutors who have conducted outreach to more than 2,500 high school students in the Lower Rio Grande Valley of Texas. Many peer tutors are active in the Health Occupations Student Association, and go on to succeed in college programs based in part on their peer tutoring experience. The program has grown from one high school at its inception, the South Texas High School for the Health Professions (known as MedHigh), to four high schools in the region, including a Science Magnet High School and a Health Technologies High School. The program successfully has engaged the Biblioteca Las Americas high school librarians with students, faculty, administrators, and community leaders to make a significant contribution to improving online health information access. The program includes curriculum development, co-teaching, and summer institutes within the schools, as well as health fairs and workshops in the local communities. The program has won several major awards, for example, from the Texas Library Association, National Commission on Libraries and Information Science, and Smithsonian Institute of Museum and Library Services.

- For more information, see <http://bla.stisd.net/viva.html>
- (E) (NLM)

Partnerships for Environmental Public Health: NIH is developing a unified program referred to as "Partnerships for Environmental Public Health" (PEPH). PEPH will support activities to build new partnerships with community groups/stakeholders, develop and/or disseminate educational and outreach materials, enhance communication with partners (i.e., town meetings, forums on selected topics), evaluate (process and outcome evaluations) strategies to quantify public health impact, or engage community and researchers in Environmental Health Science research projects. The purpose of this program is to provide support for grantees already working in this area to enhance current grant activities within the scope of the peer-reviewed application and to encourage scientists with a traditional research focus to communicate/translate their research into materials or messages that are useful to other groups, such as the lay public, health care professionals, decisionmakers, or educators. Building partnerships and translating research to communities is an important component in promoting health and preventing exposures that may have adverse human health effects. By building environmental health and science literacy, community residents are better prepared and equipped to take personal and community action to reduce exposures. Partnerships between researchers and community groups foster trust and lead to the identification of environmental health issues of concern to community residents, which may enhance the research results due to increased community participation.

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

AIDS Information Services: NIH manages the HHS-wide *AIDSinfo* service, which offers the latest federally approved information on HIV/AIDS clinical research, treatment and prevention, and medical practice guidelines that are developed by working groups under the auspices of the OAR Advisory Council. An *AIDSinfo* trans-agency steering group spans NIH, FDA, HRSA, and CDC. *InfoSIDA*, a Spanish-language version, features a customized home page and a search engine that locates Spanish-language resources within *AIDSinfo*. A new initiative to incorporate tens of thousands of

abstracts from AIDS-related conferences held over the last decade into NIH's Web-based electronic information services also is underway, and testing for the first public release of the new data was conducted in FY 2009. In addition to providing information systems, NIH supports community outreach programs for underserved communities and special populations to promote improved access to HIV/AIDS information for health professionals, patients, the affected community, caregivers, and the general public. Emphasis is placed on supporting community-based organizations, libraries, faith-based organizations, and health departments to design and implement local programs that include information access topics related to information retrieval, skills development, Internet access, resource development, and document access, e.g., through collaboration with local public libraries. In FYs 2008-2009, NIH made 25 community outreach awards.

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

Know Stroke Efforts and New Stroke Slogan: In 2004, NIH entered a partnership with CDC to launch a grassroots education program called Know Stroke in the Community. The program was designed to identify and enlist the aid of community leaders who work as "Stroke Champions" to educate their communities about the signs and symptoms of stroke and the need for immediate action. The program focuses on reaching African Americans, Hispanics, and seniors in communities that have the health care systems in place to treat stroke. To date, the program has been implemented in 12 cities, educating 184 Stroke Champions who have conducted more than 600 community events. The program was expanded this year to Charleston, South Carolina, and, as a follow-up to that program, materials will be developed for coastal communities with unique dialects. NIH also recently expanded its public education programs by collaborating with the Brain Attack Coalition (BAC) to develop a new action-oriented message that all member organizations could use with their current stroke awareness efforts. The BAC is a group of organizations committed to stroke prevention and treatment chaired by NINDS. The new slogan—"Stroke strikes fast. You should too. Call 9-1-1."—was launched in May 2009 during Stroke Awareness Month.

- For more information, see <http://stroke.nih.gov/about/>
- This example also appears in Chapter 2: *Neuroscience and Disorders of the Nervous System* and Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*
- (O) (NINDS)

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 materials on diabetes and kidney disease, respectively. For example, the NDEP encourages people to take "small steps" to prevent type 2 diabetes. The NDEP also promotes the importance of comprehensive diabetes control in its "Control Your Diabetes. For Life" educational campaign. The NKDEP encourages African American families to discuss kidney disease at family reunions, and also provides tools and resources for health care providers to help coordinate care and improve patient outcomes for kidney disease. Both programs tailor materials for minority groups at high risk.

Information Clearinghouses also provide key health information for patients, health care professionals, and the general public. A recent campaign highlighted the importance of using accurate methods to test hemoglobin A1c in people with diabetes who have sickle cell trait or other inherited hemoglobin variants. Other recent campaigns raised awareness of celiac disease and interstitial cystitis. The Weight-Control Information Network provides up-to-date, science-based information on weight control, obesity, physical activity, and related nutritional issues.

- For more information, see <http://www2.niddk.nih.gov/HealthEducation/>
- For more information, see <http://ndep.nih.gov/>
- For more information, see <http://nkdep.nih.gov/>
- For more information, see <http://win.niddk.nih.gov/>
- This example also appears in Chapter 3: *Clinical and Translational Research* and Chapter 3: *Health Communication and Information Campaigns and Clearinghouses* (E) (NIDDK, CDC)

SIDS Outreach in Minority Communities: Since 1994, when NIH launched its campaign to reduce the risks of Sudden Infant Death Syndrome (SIDS), overall SIDS rates have declined significantly, yet the disparities continue to exist. Today, babies in the American Indian and Alaska Native communities are twice as likely to die from SIDS as white infants. To help eliminate this disparity, NIH, in collaboration with Native American Management Services, Inc., developed adaptable, culturally appropriate SIDS risk-reduction materials for use in five Indian Health Service Areas—Northern Tier-Aberdeen, Billings, Bemidji, Portland, and Alaska. Under the guidance of a community-based work group, educational materials have been developed based on recommendations from the five areas. The outreach project is called "Healthy Native Babies: Honoring the Past, Learning for the Future." Project materials include a training manual and a CD-ROM. The interactive CD-ROM that has been developed includes templates for a variety of SIDS risk-reduction educational materials. It contains photographs of American Indian and Alaska Native families and infants from the five regions, taken by local photographers. These photographs can be incorporated into educational materials such as posters, flyers, brochures, and postcards.

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

Providing Science-Based Oral Health Information: NIH provides science-based oral health information tailored to meet specific needs. Two examples are described here.

- **Practical Oral Care for People with Developmental Disabilities:** Finding dental care in the community is challenging for people with developmental disabilities. Many dentists do not feel trained sufficiently to provide services to people with special needs. To help increase access to dental care, NIH developed a series of publications to equip general dentists with information they need to deliver quality oral care to persons with developmental disabilities. The series includes continuing education (CE) programs for dentists and dental hygienists and a guide for caregivers describing their important role in maintaining good oral health for their family member or client. The modules are so popular that NIH has extended the CE credit through 2011.
- **The Special Care Dentistry Association partners with NIH in this important health education outreach.** Spanish-Language Oral Health Website: A new Spanish-language website tailored for U.S. Hispanics/Latinos increases Spanish speakers' access to science-based oral health information. The site recently was tested in two cities; participants were Spanish-dominant and

bilingual Latinos with backgrounds from different countries of origin and with varying levels of education. The test was to ensure the new website is understandable, credible, and attractive to the intended audience. Other goals included understanding the approach Latinos take when seeking health information online, what they think of the quality of online health information, and whether there are significant differences between Spanish-dominant and bilingual individuals.

- For more information, see <http://www.nidcr.nih.gov/OralHealth/Topics/DevelopmentalDisabilities/>
- For more information, see <http://www.nidcr.nih.gov/espanol>
- This example also appears in Chapter 2: *Life Stages, Human Development, and Rehabilitation* and Chapter 3: *Health Communication and Information Campaigns and Clearinghouses*
- (O) (NIDCR, NICHD)

Collaboration with National Coalition of Ethnic Minority Nurse Associations

(NCEMNA): NIH conducts outreach activities focused on health disparities research through its relationship with NCEMNA. Comprised of 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, NIGMS)

Research/Outreach

Collaborative Community-Based Research: NIH is focusing on strategies and best practices for conducting collaborative community-based clinical and translational research, particularly in minority and other medically underserved communities where health disparities persist. Programs such as the Institutional Development Award (IDeA) are encouraging efforts to build and strengthen partnerships among government agencies, academic and private-sector organizations, community health providers, and organizations that also are working to improve community health outcomes. Translational, community-based research funded in several IDeA states, 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 FYs 2008 and 2009, NIH conducted workshops to gather specific recommendations from the community that are helping to shape future initiatives to enhance clinical and translational research in minority and other medically underserved communities. Workshop participants included other HHS-agencies such as AHRQ, CDC, the Indian Health Service, and HRSA.

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

- (E) (NCRR)

Community Participation in Health Disparities Intervention Research 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 (3-year planning phase, 5-year intervention phase, and 3-year dissemination phase). 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. The CBPR initiative began in FY 2005 with the award of 25 3-year research planning grants. CBPR planning grantees conducted needs assessments, focus groups, and pilot intervention studies for addressing health disparities among health disparity populations in 20 states. In FY 2008, 40 5-year intervention research grants focusing on diabetes, cancer, cardiovascular disease, substance abuse, and other diseases and conditions were awarded. This intervention phase will be followed by a competition for 3-year dissemination grants to be awarded in FY 2013. In May 2009, RFA MD-09-006, "Recovery Act Limited Competition: NCMHD Community Participation in Health Disparities Intervention Research Planning Phase," was issued for a 2-year planning research phase. Awards for this phase were made in FY 2009. Current CBPR pilot intervention research studies include:

- Suicide and alcohol use prevention among Alaska Native youth living in five communities in Alaska
- HIV/AIDS prevention among African Americans in North Carolina
- 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
- Hypertension prevention among Filipino Americans in New York City and New Jersey
- Cancer prevention among low-income Appalachian communities in Ohio by increasing colorectal cancer screening
 - For more information, see <http://grants.nih.gov/grants/guide/rfa-files/rfa-md-07-003.html>
 - For more information, see <http://grants.nih.gov/grants/guide/rfa-files/RFA-MD-09-006.html>
 - This example also appears in Chapter 3: *Clinical and Translational Research*
 - (E) (NCMHD)

Community-Based Participatory Research (CBPR): CBPR is an orientation to research that requires a collaborative approach to involve community stakeholders throughout all stages of research projects. This community input offers CBPR the potential to generate better-informed hypotheses, develop more effective interventions, and enhance the translation of research results into practice. NIH issued three funding opportunity announcements (FOAs) on CBPR in January 2008. One FOA, Community Participation in Research, solicits jointly conducted intervention research. The remaining FOAs, Community Participation Research Targeting the Medically Underserved, solicit jointly conducted research in medically underserved areas/populations; all three FOAs focus on health

promotion, disease prevention, and health disparities. A corresponding technical assistance workshop, Leap into the Community, convened February 2008 and offered comprehensive instruction from NIH program and review officials on the CBPR approach and preparing responsive applications to the FOAs. Outreach and training activities on CBPR have included the creation of an educational brochure (November 2007); organization of two special sessions at annual scientific meetings for the Society of Behavioral Medicine and the American Sociological Association on the principles and efficacy of CBPR and showcasing successful NIH-funded research projects (March 2008 and August 2009, respectively); and planning of the 2009 NIH Summer Institute on Community-Based Participatory Research Targeting the Medically Underserved, which addresses essential issues inherent in conducting community-partnered research with medically underserved areas/populations (August 2009).

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-08-074.html>
- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-08-075.html>
- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-08-076.html>
- For more information, see http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/CBPR_TA_Wrkshp.aspx
- For more information, see http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/CBPR_ASA.aspx
- For more information, see <http://conferences.thehillgroup.com/si2009/index.html>
- For more information, see http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/index.aspx
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (OBSSR, CDC/NIOSH, NCI, NHLBI, NIAAA, NIAMS, NICHD, NIDA, NIDCD, NIDCR, NIEHS, NIMH, NINR, ORWH)

Research Partnerships: Fostering partnerships is a key component of the multifaceted NIH strategic approach to eliminating health disparities. NCMHD funds a broad range of collaborations with the other NIH ICs and other Federal agencies. NCMHD co-funded projects leverage the existing strengths, resources, and research potential of key Federal research partners. Since 2001, NCMHD has devoted more than \$300 million to support several hundred research, training, community outreach, and capacity-building projects. Examples include:

- *The Jackson Heart Study* (with NHLBI) is a population-based longitudinal cohort study of African Americans examining genetic, biological, and environmental risk factors for the development and progression of cardiovascular disease. The study is the largest single-site, prospective, epidemiologic investigation of cardiovascular disease among African Americans ever undertaken. Currently, follow-up data collection is ongoing to include 4000 CT scans by December 2009.
- *The Sister Study* (with NIEHS), is a national study investigating environmental and genetic breast cancer risk factors. The Sister Study is the only long-term study in the United States and Puerto Rico of women aged 35 to 74 whose sisters had breast cancer. Begun in 2003, the study is prospectively examining the environmental and familial risk factors for breast cancer and other diseases in a cohort of 50,000 sisters of women who have had breast cancer.
- *The Navajo Bone Health Study* (with NIAMS) is focusing on the surveillance of bone health in the Navajo Nation. These efforts in time will enable the Navajo Nation to plan screening and culturally appropriate education and intervention programs targeted toward the segments of the population at greatest risk for fracture or osteoporosis.

- *Racial and Ethnic Approaches to Community Health Across the U.S. (REACH U.S.)* is a CDC program promoting community coalitions that design, implement, evaluate, and disseminate community-driven strategies to eliminate health disparities in key health areas. In FY 2009 NIH supported a REACH US initiative with Morehouse School of Medicine and its partners to increase breast and cervical cancer screening among African American women in North Carolina and South Carolina. Also, NIH funding to Virginia Commonwealth University promoted prenatal care in African American women in Virginia.
- *Interventions for a Focused Diabetes and Chronic Kidney Disease (CKD) Disparities Project* is a CMS initiative improving the quality of care for Medicare beneficiaries through interventions that will improve diabetes measures and detect the incidence, decrease the progression, and improve care of those with CKD, in a targeted underserved population. NCMHD funding has been supporting the development of intervention research projects within the Mississippi Delta Region.
 - (E) (NCMHD, CDC, CMS, NHLBI, NIAMS, NIEHS)

Getting Proven Treatments into the Criminal Justice System: Unfortunately, most inmates in need of substance abuse treatment do not receive it while in prison and, upon their release, continue a vicious cycle of drug use and crime. In response, NIH—along with multiple Federal agencies and health and social service professionals—is working systematically to move science-based treatment interventions into the criminal justice system, where they can have a major impact. In a Delaware Work Release study, those who participated in prison-based treatment followed by aftercare were 7 times more likely to be drug free after 3 years than those who received no treatment. Other research supported under the Criminal Justice-Drug Abuse Treatment Studies (CJ-DATS) affirms the critical need for prisoners to receive effective substance abuse treatment while incarcerated and during their re-entry into the community. A recent randomized clinical trial found that prisoners who began methadone maintenance treatment in prison were significantly more likely after 12 months post-release to continue treatment and decrease drug use and criminal activity than a counseling-only group. A related issue for this population is heightened HIV risk—the U.S. prison system also being where many inmates first receive HIV testing and initiate treatment. However, only a nominal percentage continues this treatment following release. New research shows that simply providing formal assistance in filing the paperwork for antiretroviral treatment medications can promote greater continuity of HIV pharmacotherapy among released inmates. Gaining insight into ways to reduce drug use and criminal recidivism—including among adolescents for whom the same issues apply—as well as limit HIV spread in communities means huge economic and social cost savings.

- Baillargeon J, et al. *JAMA* 2009;301(8):848-57. PMID: 19244192.
- Chandler RK, et al. *JAMA* 2009;301(2):183-90. PMID: 19141766. PMID: PMC2681083.
- Kinlock TW, et al. *J Subst Abuse Treat* 2009;37(3):277-85. PMID: 19339140. PMID: PMC2803487.
- Martin SS, et al. *Prison J* 1999;79(3):294-320.
- For more information, see <http://www.cjdats.org/>
- For more information, see <http://www.drugabuse.gov/Blending/>
- This example also appears in Chapter 2: *Infectious Diseases and Biodefense* and Chapter 3: *Clinical and Translational Research*
- (E) (NIDA) (GPRA)

Rural Latino Preschooler's Oral Health: Intersections among Family, Community, Providers and Regulators: Latino children experience among the highest prevalence of early

childhood dental caries in the United States. Researchers explored the intersections among four societal sectors or contexts of care that potentially contribute to oral health disparities for low-income, preschool Latino children in rural California. The ethnographic investigation was conducted in a predominately Mexican-American agricultural community. Observations occurred in homes, community facilities, and dental offices, and were supplemented with in-depth interviews by trained anthropologists with key community informants and primary caregivers of children less than 6 years old. Factors that significantly intersected to produce or sustain poor oral health care for children follow. Caregivers did not always recognize signs of decay among their children, nor quickly respond unless children also complained of pain. Fluctuating eligibility for health insurance intersected with limited community infrastructure and civic amenities, including lack of public transportation, to create difficulties in access to care. Nonfluoridated bottled water often was consumed rather than tap water because of fears about potential pesticide pollution of the municipal water supply. Multiple dental visits caused parental hardship and occasionally resulted in the loss of the caregiver's job. Dental fear and poor provider-caregiver communication were exacerbated by a scarcity of dentists willing to serve rural low-income populations. Such empirical research related to newly emerging conceptual models is greatly needed. Understanding that multiple, intersecting factors at numerous levels will inform intervention research customized to the individual, community, and society.

- Barker JC, Horton SB. *BMC Oral Health* 2008;8:8. PMID: 18377660. PMCID: PMC2362117.
- For more information, see <http://www.nidcr.nih.gov/DataStatistics/FindDataByTopic/DentalCaries/DentalCariesChildren2to11>
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (NIDCR)

Understanding and Promoting Health Literacy: Low health literacy is a widespread problem, affecting more than 90 million adults in the United States, where 43 percent of adults demonstrate only the most basic or below-basic levels of prose literacy. Low health literacy results in patients' inadequate engagement in decisions regarding their health care and can hinder their ability to realize the benefits of health care advances. Research has linked low or limited health literacy with such adverse outcomes as poorer self-management of chronic diseases, fewer healthy behaviors, higher rates of hospitalizations, and overall poorer health outcomes. An NIH 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. In December 2008, a grantee meeting was convened to provide a venue for NIH-funded scientists conducting health literacy research to discuss lessons learned about health literacy-related topics, including measurement and methodology, actionable research (e.g., plain language, dissemination), and special populations (e.g., cognition, culture, and socioeconomic status). NIH is planning a fall workshop to highlight the state-of-the-science and to inform directions for reissuing the funding opportunity announcement in 2010.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-07-020.html>
- For more information, see http://obssr.od.nih.gov/scientific_areas/social_culture_factors_in_health/health_literacy/index.aspx
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (OBSSR, AHRQ, NCI, NHLBI, NIA, NIBIB, NICHD, NIDCD, NIDCR, NIEHS,

NIMH, NINR, NLM)

Research Training

Minority Health and Health Disparities International Research Training (MHIRT)

Program: In 2009, NIH provided funding for the MHIRT Program, which allowed 22 academic institutions to administer international training opportunities in health disparities research for more than 150 undergraduate and graduate students. The current funding cycle builds on the success of previous MHIRT Program activities and contributes to the elimination of health disparities in the United States by developing a cadre of health disparities researchers with international experience. Many MHIRT subjects are engaged in research that investigates the use of biomedical processes in eliminating health disparities, genetics, pharmaco-dynamic trends, socioeconomic, behavioral, psychosocial, and other fundamental determinants of health disparities. The trainees are placed worldwide at foreign collaborating sites in Argentina, Australia, Botswana, Brazil, Chile, China, Czech Republic, Dominican Republic, Ecuador, England, Ethiopia, Finland, France, Germany, Ghana, Guatemala, India, Italy, Jamaica, Japan, Mexico, New Zealand, Peru, Poland, Republic of Georgia, Romania, Slovak Republic, South Africa, South Korea, Spain, Swaziland, Sweden, Thailand, Uganda, and Vietnam. African American and Hispanic undergraduate and graduate students constitute the largest racial and ethnic groups participating in MHIRT training programs.

- (E) (NCMHD)

NIH Research Supplements to Promote Diversity in Health-Related Research: These supplements have broad eligibility criteria designed to support and recruit students, postdoctorates, and eligible investigators from diverse backgrounds underrepresented in the biomedical, behavioral, and clinical and social sciences research workforce. The program specifically seeks to recruit and retain individuals from diverse backgrounds underrepresented in biomedical research, including (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 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. NIH believes that diversity in the biomedical, behavioral, clinical, and social sciences research workforce will bring a more balanced perspective to the determination of research priorities, increased diversity in clinical trials, and a new synergy to the study of health disparities.

- For more information, see <http://grants.nih.gov/grants/guide/pa-files/PA-08-190.html>
- (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, 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. As of 2006 (the most recent year for which data are available), 197 RCMAR scholars from diverse backgrounds had been funded across 6 sites. A recent independent evaluation of the RCMARs found that 74 percent of the scholars between 1997 and 2005 had published at least 1 article in a peer-reviewed journal after joining a RCMAR, and 57 percent were first authors. Whereas only 13 percent of RCMAR participants had received a Public Health Service grant prior to joining the program, 28 percent received 1 or more after joining the program. RCMAR scholars and affiliated faculty have published 78 scholarly articles and 2 special issues of journals on recruitment and retention of minority elders in clinical trials, and have developed an active website on measurement, conducted 2 conferences on this topic, and published many articles relating to the development of culturally sensitive measures of health status.

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

Loan Repayment Program for Health Disparities Research: To promote a diverse and strong scientific workforce effectively, it is necessary to expand and create transitioning and financial aid programs, which help alleviate barriers that discourage many students from pursuing a research career. The Loan Repayment Program for Health Disparities Research (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 Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds (ECR-LRP) seeks 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, NIH will work to establish links between the MHIRT program, LRPs (LRP and ECR-LRP), and NIH research priorities. In 2009, NIH made awards to 314 participants.

- (E) (NCMHD)

Collaborations Between Minority-Serving Institutions and Cancer Centers: The Minority Institution (MI)/Cancer Center (CC) Partnership (MI/CCP) is a flagship program that has been instrumental in establishing strong collaborations between minority-serving institutions (MSIs) and CCs. In its 2008 report, the MI/CCP Program Evaluation Committee, an external panel of investigators and faculty, considered MI/CCP to be a model program that has fostered strong cancer research partnerships throughout the United States. This Partnership established new cancer research curricula, recruited new faculty, increased awareness about health care disparities and cultural sensitivities, and developed programs and outreach efforts in educating underserved communities. The MI/CCP has provided outreach education and training to individuals at all levels including postdoctoral fellows, medical students, graduate students, students at master's level, and baccalaureate and high school students. Establishing new collaborations and partnerships in communities has been a hallmark of this program, culminating in increases in numbers of awarded grant applications and numbers of manuscripts, oral presentations, and poster presentations at both regional and national levels. Many research advances are emerging from the Partnership. For example, through the Morehouse School of Medicine and University of Alabama Partnership, researchers have identified a possible genetic cause for increased risk for a more advanced form of colorectal cancer in blacks that leads to shorter survival. Understanding the relationship between

molecular defects and differences in colorectal cancer incidence, aggressiveness, and clinical outcomes is important in individualizing the treatment and in eliminating racial disparities.

- For more information, see <http://crchd.cancer.gov/research/miccp-overview.html>
- For more information, see <http://clincancerres.aacrjournals.org/cgi/content/full/15/7/2406>
- This example also appears in Chapter 2: *Cancer*, Chapter 3: *Molecular Biology and Basic Research* and Chapter 3: *Clinical and Translational Research*
- (E) (NCI)

Research Capacity

Expanding NIH's Capacity to Conduct Minority Health and Health Disparities Research:

- *Health Disparities Research on Minority and Underserved Populations (R01) Program*: NIH established this program in FY 2009 to implement the science, practice, and policy paradigm and enhance its focus on building the science and health professions workforce for health disparities. It provides an additional means for supporting innovative research projects. A total of eight awards were made in FY 2009.
- *NCMHD Intramural Research Program*: The NCMHD Intramural Research Program (IRP) was approved in FY 2009. An on-campus program, the IRP will: (1) conduct state-of-the-art research focusing on the linkage between biological and nonbiological determinants of health in health disparity populations; (2) create training and mentorship opportunities; and (3) contribute to the diversity of early-stage and seasoned investigators at NIH.
- *Disparities Research and Education Advancing our Mission (DREAM) Program*: Launched in FY 2009, this career development program aims to retain promising investigators in health disparities research careers, including those who have successfully completed the Loan Repayment Program for Health Disparities Research.
- *American Recovery and Reinvestment Act (ARRA)*: Under ARRA, the NCMHD has developed significant new health disparities research and research capacity-building opportunities. The NCMHD "Grand Opportunities" grants support high-impact ideas that lend themselves to short-term funding and may lay the foundation for new fields of investigation. Challenge grants address specific knowledge gaps, scientific opportunities, new technologies, data generation, or research methods. The Grand Opportunities and Challenges grants support: clinical research efforts, comparative effectiveness research examining approaches that address access barriers, wireless technologies research, research on ethical issues and health disparities, and other research on health disparities factors. Other initiatives established under ARRA include a Dissertation Research Award.
 - (I) (NCMHD)

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 mandated the creation of this unique program in the legislation that created the NCMHD (Pub. L. No. 106-525). This program makes significant investments in the education and training of individuals from diverse backgrounds, including racial/ethnic minority and other individuals from health disparity populations who are underrepresented in the scientific workforce. NCMHD-endowed institutions are using endowment funds to enhance research capacity and infrastructure for research and training by

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: (Note: The RIMI program will be replaced by the Building Research Infrastructure and Capacity [BRIC] program in FY 2010.) The RIMI program establishes and improves the scientific infrastructure at nonresearch intensive academic institutions. RIMI provides resources to strengthen faculty-initiated research programs, enhance academic development of students in science and mathematics, and improve the capacity for training future research scientists.

The RIMI program supports building research capacity in 2-year colleges and other nonresearch intensive academic institutions that only offer associate's degrees, baccalaureate, and/or master's degrees in the basic, life, behavioral, or social sciences. The RIMI program enables an institution to:

- Strengthen its basic research infrastructure and the institution's science programs;
- Institute a comprehensive faculty development research training program;
- Establish an academic career development training program for students interested in pursuing a career in the biomedical sciences; and
- Support individual faculty-initiated research projects that may lead to the development of independent researchers in minority health and health disparities.

The RIMI program helps nondoctoral degree-granting institutions develop and enhance their research infrastructure and their capacity and competitiveness to conduct biomedical, clinical, and/or behavioral research.

- For more information, see <http://grants.nih.gov/grants/guide/rfa-files/RFA-MD-08-002.html>
- (E) (NCMHD)

Research Centers in Minority Institutions (RCMI): The RCMI program has developed and enhanced the research infrastructure of minority-serving institutions by expanding human and physical resources for conducting basic, clinical, and translational research. It 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." The RCMI program has provided resources to acquire advanced instrumentation, renovate laboratory facilities, and improve research infrastructure. Additionally, it has enhanced faculty development, funded pilot projects, and supported core facilities. Because many RCMI investigators study diseases that disproportionately affect minorities, NIH support has brought more minority scientists into mainstream research and enhanced biomedical research focused on improving the health of racial and ethnic minorities and other

medically underserved populations. The RCMI program includes various types of awards to help improve research capacity and reduce health disparities. For example, the RCMI Translational Research Network has fostered collaboration among researchers, developed and shared practices in disease prevention in local communities, and funded informatics tools for managing clinical research data. The RCMI program also has supported Clinical Research Education and Career Development awards that provide didactic training and mentor clinical research experiences to develop independent researchers.

- For more information, see <http://www.ncrr.nih.gov/rircmi>
- For more information, see <http://www.ncrr.nih.gov/rtrn>
- For more information, see <http://www.ncrr.nih.gov/crecd>
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (NCR, NCMHD, NHLBI, NIA, NIAMS, NICHD, NIDA, NIDDK, NIMH)

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 with historically low NIH funding. The IDeA program supports multidisciplinary centers and statewide 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 the Lariat Networking Project, a pilot program that has enabled connectivity in six IDeA states in the Northwest (Alaska, Hawaii, Idaho, Montana, Nevada, and Wyoming) in partnership with the University of Washington and the University of California, San Diego. The Louisiana Optical Network Initiative (LONI) followed, supporting high bandwidth connectivity in Louisiana and Mississippi. Recently, five IDeA states have formed the North East Cyberinfrastructure Consortium (Delaware, Maine, New Hampshire, Rhode Island, and Vermont). IDeANet ultimately will enable all institutions in the IDeA program to engage in national and international collaborations.

- For more information, see <http://www.ncrr.nih.gov/riidea>
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (NCR) (GPRA)

Clinical and Translational Science Award (CTSA) Program Progress: Launched in 2006, NIH has made significant progress in building a national consortium for clinical and translational research. Since 2008, 22 new CTSA joined the consortium, adding representation from eight new states, additional pediatric expertise, and greater informatics capabilities. At the national level, the CTSA consortium has identified five strategic goals: developing strategies and resources to move laboratory discoveries into early clinical testing (T1 translation), reducing complexities and improving ways clinical and translational research is conducted, enhancing training and career development of clinical and translational investigators, encouraging consortium-wide collaborations, and improving the health of communities across the nation—with an emphasis on community engagement and comparative effectiveness research. Working together, the consortium has made substantial progress in improving the management of clinical research, developing core competencies in clinical and

translational science, and accelerating the dissemination of research findings into clinical practice. The momentum of the CTSA consortium continues to build as new connections are emerging rapidly within, across, and beyond the consortium. For example, CTSA are connecting with the following NIH-funded institutions: Emory University (Atlanta, Georgia) is partnering with Morehouse School of Medicine; Vanderbilt University (Nashville, Tennessee) is partnering with Meharry Medical College; and Weill Cornell Medical College (New York, New York) is partnering with Hunter College.

- For more information, see <http://www.ncrr.nih.gov>
- For more information, see <http://www.ctsaweb.org>
- For more information, see http://www.ncrr.nih.gov/ctsa/progress_report_2009
- This example also appears in Chapter 3: *Clinical and Translational Research*
- (E) (NCR) (ARRA)

ARRA-Funding Expands Research Capabilities: NCR is using its ARRA funds designated for scientific research to accelerate the Center's research priorities and support research, resources, tools, and training to help researchers funded by NIH transform basic discoveries into improved human health. In contrast to most of the NIH ICs that fund primarily Research Project Grants (i.e., R01s), NCR primarily supports large Center programs that build research capacity and offer training and career development. Consistent with NCR's research portfolio, a few previously reviewed Research Project Grants (R01s and R21s) are being awarded with ARRA funds. Through competitive revision awards, NCR is encouraging NIH-funded researchers (primarily supported by other NIH ICs) to leverage the resources, expertise, and infrastructure of NCR centers and Center-like programs. To further advance the scientific progress of NCR programs, administrative supplements are being awarded to: advance translational (pre- and post-clinical) research, achieve CTSA consortium strategic goals, enhance NCR pilot project mechanisms, promote collaborative community engagement research, improve research workforce development, and strengthen science education and dissemination. A new ARRA-supported initiative will develop infrastructure to connect people and resources across the Nation and promote interdisciplinary collaborations and scientific exchange. Additional ARRA funding is supporting NIH-led activities such as the Challenge Grants and the Summer Research Experiences for Students and Science Educators. From the beginning of the ARRA-funding strategy development, NCR leadership decided to align its ARRA activities broadly with the goals and objectives of the NCR 2009-2013 Strategic Plan.

- For more information, see <http://www.ncrr.nih.gov/recovery>
- For more information, see http://www.ncrr.nih.gov/strategic_plan/implementation/
- This example also appears in Chapter 3: *Clinical and Translational Research* and Chapter 3: *Technology Development*
- (E) (NCR) (ARRA)

NIH Strategic Plans Pertaining to Minority Health and Health Disparities Research

NIH-Wide Strategic Plan

- [NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008](#)

The NIH Health Disparities Strategic Plan, Fiscal Years 2009-2013 is being developed. The NIH Health Disparities Strategic Plan Working Group, comprised of eminent leaders in minority health and

health disparities research, has been convened by the NCMHD Director to guide the development of this new plan. Upon completion, the new plan will be posted to RePORT.

Note: Every IC has a Strategic Plan on Health Disparities. These plans are contained with the NIH plan. Nonetheless, because several ICs also separately publish those plans and others that address defined populations that are subject to health disparities, we are listing these separately published plans here.

Office of AIDS Research (OAR)

- [*FY 2008 Trans-NIH Plan for HIV-Related Research*](#)
- [*FY 2009 Trans-NIH Plan for HIV-Related Research*](#)
- [*FY 2010 Trans-NIH Plan for HIV-Related Research*](#)

National Institute of 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 Five-Year Strategic Plan 2009*](#)
- [*Strategic Plan on Reducing Health Disparities*](#)

National Institute of Dental and Craniofacial Research (NIDCR)

- [*NIDCR Strategic Plan*](#)
- [*NIDCR Implementation Plan*](#)

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

- [*Strategic Plan on Minority Health Disparities*](#)

National Institute of Environmental Health Sciences (NIEHS)

- [*Worker Education and Training Program \(WTEP\) Strategic Plan 2008-2013*](#)