

# NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES

## MISSION

The mission of the National Center on Minority Health and Health Disparities (NCMHD) is to promote minority health and to lead, coordinate, support, and assess the NIH effort to reduce and ultimately eliminate health disparities. In this effort the NCMHD will conduct and support basic, clinical, social, and behavioral research; promote research infrastructure and training; foster emerging programs; disseminate information; and reach out to minority and other health disparity communities.

## VISION

The NCMHD envisions an America in which all populations will have an equal opportunity to live long, healthy and productive lives.

## OVERVIEW OF NCMHD'S ROLE IN ADDRESSING HEALTH DISPARITIES

Despite improvements in the overall health of the American people, ethnic and racial minorities and other underserved populations suffer from significant disparities in the burden of illness and premature death. These health disparities are not limited to one or two disease categories. They apply to a broad spectrum of disease types that include infectious diseases, vascular diseases, endocrine diseases, arthritic diseases, connective tissue diseases, malignancies, and mental illnesses. Some of the diseases disproportionately affecting minorities and the poor are listed in Figure 1: Sample of Disparities in Health.

While research is critical to understanding the causes of disparities and identifying ways to reduce and ultimately eliminate disparities among populations, research alone will not solve the health disparity problem. To fully address the health disparity problem, the NIH and the NCMHD will combine research with enhanced efforts to reach out to minority and underserved populations in order to bring the fruits of that research to those communities. Furthermore, the NCMHD will continue efforts to strengthen the infrastructure supporting minority and health disparity research and increase minority involvement in research, both as researchers and as participants in clinical trials.

### Transition from ORMH to NCMHD

In its role within the NIH Office of the Director, the former Office of Research on Minority Health (ORMH) worked with stakeholders across the Nation and within the

#### Figure 1: Sample of Disparities In Health

**Cancer** – Minority groups suffer disproportionately from cancer. The difference in cancer mortality is about 12% higher for Hawaiian men and 20% higher for Hawaiian women than that of white Americans. Asian Americans have substantially higher mortality rate from stomach cancer than do Whites.

**Mental Health** – Disease burdens associated with mental disorders fall disproportionately on ethnic minority populations. Native American and Alaskan Natives not only suffer disproportionately from depression, but these populations also experience higher rates of suicide.

**Obesity**– Is a growing epidemic for all Americans and leads to premature death from heart disease, stroke, Type 2 diabetes and certain cancers. However, as the prevalence of obesity in ethnic minority populations such as African Americans, Hispanics, and Native Americans is at least 50 to 100% higher than Whites, these groups suffer disproportionately from obesity related diseases.

**Type 2 Diabetes** – Racial and ethnic minorities not only have a prevalence of Type 2 diabetes that is 200 to 500% higher than Whites, they also suffer disproportionately from severe and debilitating complications of diabetes such as blindness, heart disease, amputations, and renal failure.

**Heart Disease and Stroke**– Coronary heart disease mortality in middle-aged Asian/Pacific Islanders is 30% to 40% higher than compared to Whites. The incidence of stroke is also higher in African Americans, and their mortality rate is nearly 80% higher than that of Whites. The mortality rate for strokes is 50% higher in Vietnamese Americans than that for Whites.

**HIV and AIDS** – In 1998, 45% of reported AIDS cases were among African Americans, compared with only 33% among Whites. Latina women are infected with AIDS at a rate that is seven times higher than that for white women. By the end of 1998, 77% of AIDS infected women were members of minority groups, and 57% of these women were African American women.

**Infant Mortality** – During the last decade, the African American infant mortality rate has been double that of Whites, even when it is controlled for socioeconomic factors. The infant mortality rate among Native Americans remains 40% higher than that among Whites, and among Puerto Ricans, it remains 15% higher than that among Whites.

government to develop the Minority Health Initiative, which subsequently guided the NIH minority research efforts. Over a ten-year period, the ORMH was able, through collaborations with the NIH Institutes and Centers (ICs), to identify many projects and initiatives to improve the health of minorities and to provide additional funding to supplement IC funding in addressing minority health issues.

Furthermore, during the past decade generous funding of biomedical and behavioral research by the U.S. Congress has contributed to scientific advances to improve health and quality of life. However, at the same time the U.S. Congress and the American people have become increasingly aware that minorities and other populations have not equally benefited from our Nation's progress in scientific discovery.

To meet this challenge, the U.S. Congress enacted Public Law (P.L.) 106-525 the Minority Health and Health Disparities Research and Education Act of 2000, creating the NCMHD. The NCMHD represents a significant evolution of the ORMH. The NCMHD is an equal partner with the other NIH Institutes and Centers. Furthermore, with its generous funding and new authorities, the NCMHD will be able to build upon the collaborative research endeavors initially undertaken by the ORMH and the NIH Institutes and Centers.

P.L. 106-525 identifies a number of responsibilities that the NCMHD must carry out in its role to coordinate the NIH efforts of addressing minority health and other health disparities. To support this broad coordination requirement, the NCMHD will focus its efforts across three primary initiatives:

- Establish and regularly update a comprehensive strategic plan and budget encompassing all NIH minority health and other health disparity research activities.
- Provide mandated reports evaluating progress made by the NIH in addressing minority health and other health disparities.
- Coordinate NIH minority health and other health disparity research, infrastructure and outreach activities.

Through these efforts, the NCMHD will ensure the coordination of NIH activities in addressing minority and other health disparity populations and disseminate information to these populations and other stakeholders with the intent of reducing the health disparity gap in the United States.

#### **Establish and regularly update a comprehensive strategic plan and budget encompassing all NIH minority health and other health disparity research activities**

According to P.L. 106-525, the Director of the NCMHD, in collaboration with the NIH Director and IC Directors, is responsible for the oversight and development of a comprehensive NIH-wide plan and budget highlighting the collective efforts of all the NIH ICs in addressing minority health and other health disparities. With input from each IC, the plan must: 1) establish priorities among health disparity research activities conducted throughout the NIH; 2) give priority to the expenditure of funds to conduct and support minority health disparity research; and, 3) describe the means for achieving stated objectives, the dates objectives are expected to be achieved, and the anticipated funding required to accomplish the objectives.

To develop the NIH-wide plan and budget the NCMHD will ensure close cooperation and coordination with each of the NIH ICs. The plan and budget will serve as a broad binding

statement of policies regarding minority health and other health disparities research activities of the NIH. The NCMHD will update the NIH-wide strategic plan annually.

Prior to the establishment of the NCMHD, the NIH and the ORMH recognized the need to engage the public in developing strategies to reduce health disparities across America. Consequently, the ORMH-sponsored a conference in April of 2000 to identify ways to improve biomedical research and training opportunities for minority populations. Over 1,000 participants from minority communities, the general public, and the NIH institutes and centers attended the conference and provided a series of recommendations. From October 2000 to February 2001 the NCMHD posted the first draft of the Trans-NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities on its website for public comments. The NCMHD considered the public comments and recommendations from both the April 2000 conference and the responses to the web posting of the draft plan in developing the final plan.

### **Provide mandated reports evaluating progress made by the NIH in addressing minority health and other health disparities**

In addition to developing an NIH-wide strategic plan and budget for addressing minority health and other health disparities, the Public Law also tasks the Director of the NCMHD with developing and supporting several additional reports. As the lead coordinator of minority health and other health disparities research throughout the NIH, the Director of the NCMHD will monitor and report on the progress of research efforts, evaluate coordination efforts throughout the NIH, determine the resources needed, and describe a means to measure the needs, current activities, and private sector activities as they relate to minority health and other health disparities. The NCMHD will:

- Develop annual reports describing and evaluating the progress made and funds expended in health disparities research conducted or supported by the national research institutes [P.L. 106-525, Title I, Section 101] – Due FY02 and thereafter annually
- Assist the Secretary of HHS and the Director of the NIH in developing a report to determine the effectiveness of NCMHD coordination in addressing health disparities; evaluating the extent to which the NCMHD efforts have helped reduce the duplication of administrative resources among ICs; and providing recommendations concerning future legislative modifications with respect to minority health disparities research [P.L. 106-525, Title I, Section 104] – Due November FY06
- Develop a report providing recommendations for the methodology that should be used to determine the extent of NIH resources that are dedicated to minority health and other health disparities research. [P.L. 106-525, Title I, Section 105] – Due December FY03

### **Coordinate NIH minority health and health disparity research, infrastructure and outreach activities**

P.L. 106-525 also requires the Director of the NCMHD to act as the primary federal official with responsibility for coordinating all minority health disparities research and other health disparity research conducted or supported by the NIH. In this role, the Director will represent the health disparities research programs of the NIH at all relevant Executive branch taskforces and committees. Additionally, the Director will maintain communications with all relevant Public Health Service agencies and ensure the timely transmission of minority health and other health disparity information among various agencies.

## NCMHD Areas of Emphasis and Objectives

In accordance with NIH's established strategic direction to reduce and ultimately eliminate health disparities, the NCMHD has categorized its strategic objectives across three areas of emphasis. Although the NCMHD will initiate efforts in each area of emphasis, the NCMHD will make the development and implementation of its infrastructure programs a priority for the current fiscal year.

### ▪ **Research Area of Emphasis:**

- *Research Objective One:* Establish research priorities
- *Research Objective Two:* Conduct and support foundational research, such as developing population specific survey instruments that will serve the NCMHD and other Centers in their efforts to do health disparity research
- *Research Objective Three:* Conduct and support research, such as intervention studies that may have a direct impact on closing health disparities
- *Research Objective Four:* Conduct and support research that helps develop innovative means of outreach/communication and measures the efficacy of outreach efforts

### ▪ **Research Capacity and Infrastructure Building Area of Emphasis:**

- *Research Capacity Objective One:* Develop a cadre of competent researchers with expertise in minority health and other health disparities research
- *Research Capacity Objective Two:* Promote and support research capacity-building activities in racial and ethnic minority and medically underserved communities
- *Research Capacity Objective Three:* Develop and refine research tools, survey instruments, and databases that are culturally sensitive, competent and specifically designed for minority populations

### ▪ **Outreach Area of Emphasis:**

- *Outreach Objective One:* Outreach That Engages Communities and their Community-Based Organizations
- *Community Outreach Objective Two:* Outreach That Engages Health and Social Service Professionals
- *Outreach Objective Three:* Outreach That Engages Health, Research and Social Service Institutions, Professional Organizations and the Business Sector

## A Note on Performance and Outcome Measures

The NCMHD developed performance and outcome metrics for each major objective in each area of emphasis. Developing useful performance and outcome assessment tools can be challenging, particularly in the area of basic research, which is discussed in greater detail below. The NCMHD faces special challenges in this regard because it is a new Center in the early stages of program development. Constructing outcome metrics for programs that do not yet exist are necessarily speculative in nature and subject to modification. In an effort to assess performance, the NCMHD will use two quantitative metrics: 1) milestones and 2) performance measures. Milestones generally track action plans and provide temporal targets for the completion of tasks. Completion of tasks on time and on budget is an important indicator of performance. Additionally, the milestones provide an indication of the prioritization of efforts and when they are expected to be completed. The second category, performance measures, attempts to capture anticipated improvements in performance over time. These may reflect improvements in productivity, efficiency or other favorable targets and may be expressed as a percentage improvement or an improvement in absolute numbers. The dynamic nature of performance measures makes them subject to ongoing revision and refinement especially in an organization that has just recently been created.

As noted above, assessing performance and outcomes in the domain of basic science presents special challenges because the process of discovery is, by definition, steeped in uncertainty. Furthermore, the value of basic science discoveries may not be fully evident for decades.

The NCMHD has therefore added a qualitative measure of performance and outcomes to complement the quantitative measures described above. The qualitative approach is derived from recommendations made by a joint committee composed of the National Academy of Sciences, the National Academy of Engineering and the Institute of Medicine.

It is the opinion of that committee that there are meaningful measures of quality, relevance, and world leadership in a scientific field (benchmarking), which are reasonable predictors of the eventual usefulness of basic science research. In judging quality, relevance and leadership, the committee recommended an expert review process. While peer review is commonly applied to individual projects, the intent here is to apply it to entire programs. In the case of judgments regarding relevance, potential benefactors of research and other key stakeholders should be included in the deliberations.

- **Performance Measures:** Shorter term objectives that move us towards the longer term primary outcome measure
- **Outcome Measures:** Enables an organization to quantify or measure success in accomplishing its fundamental mission. In this case, it is reducing or eliminating health disparities

It should be emphasized that these qualitative measures are not meant to replace quantitative assessments of research performance and outcomes, but to complement them and to paint a more complete picture of performance.

Therefore the performance metrics we developed for research fall into three categories: 1) *Milestones*, which are target dates for completing steps in the research action plans; 2) *Performance Measures*, which track growth in surrogate measures for research productivity; and 3) *Expert Review Measures*, which rely on the opinion of expert panels that judge research on the basis of quality, relevance and leadership. Expert review may be employed as either performance or outcome measures, or both.

## 1.0 AREA OF EMPHASIS: RESEARCH

Over the last century the average American lifespan increased by approximately thirty years. This is due, in part, to remarkable advances in biomedical science and research. As a world leader in biomedical research, the NIH has contributed significantly to these advances. However, the bounty of this research, improved health and greater longevity, has not been equally enjoyed by all Americans. Certain racial and ethnic minorities, as well as other underserved populations, suffer from a greater burden of disease and premature death. Over the last decade, the NIH began to address the issue of health disparities through expanded research initiatives. And, in the last year, the commitment to health disparity research has undergone a quantum increase as the NCMHD replaced the ORMH.

One of the more significant differences between the ORMH and the NCMHD is the authority of the NCMHD to independently support and conduct intramural and extramural research. Additionally, the organization's mission was broadened to include other health disparity groups, in particular the underserved. This section describes the principle research objectives for the NCMHD. They are:

- Establish research priorities
- Conduct research to better define the health disparity research domain and develop survey instruments that are population-specific
- Conduct and support research that may have a direct impact on closing health disparities
- Develop methodologies to effectively conduct outreach and measure the impact of outreach efforts

The NCMHD research objectives are, to a large extent, sequential in nature. Therefore, over the next year the NCMHD will make formulating its research priorities its primary focus, an exercise that will require ongoing adjustments. The research supported by the NCMHD will be, to a significant extent, interdisciplinary in nature, combining basic biomedical research with behavioral and social science research. This interdisciplinary approach addresses the multifactorial nature of health disparities. Furthermore, the research supported by the NCMHD will include both "targeted" studies that enroll only those populations experiencing health disparities, and "inclusion" studies that over-sample populations experiencing health disparities. As part of its research program, the Center is continuing to fund a number of initiatives developed under the auspice of the ORMH. Moving forward, the Center will consider the ongoing partnership programs in evaluating its research priorities.

### 1.1 Research Objective One: Establish research priorities

As a new Center, the NCMHD has authority to fund research projects independently of the other ICs. Proper priority-setting will ensure that the finite resources devoted to the research endeavor are expended in the most cost efficient manner, and best serve those suffering from health disparities. Setting these priorities requires a thorough understanding of what research has already been done, and where there are significant gaps in health disparity research. Setting these priorities will also require significant input from minority and other health disparity communities, as well as the professional and scientific communities. The NCMHD research priorities must also reflect priorities established by Congress and the broader federal effort to

eliminate health disparities. In that regard, these priorities must take into account specific diseases conditions and issues previously identified by the federal government. These include: diabetes, hypertension, infant mortality, cancer screening, immunization, glomerular disease, osteoporosis, and breast cancer. Finally, where possible, it is important to identify and prioritize long-term goals for the measurable reduction of disparities in specific diseases and conditions.

### 1.1.1 Action Plan and Milestones

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Review priorities from other IC submissions and ongoing projects initially funded by the ORMH and begin investigation of areas of overlap</li> </ul>	FY02	X
<ul style="list-style-type: none"> <li>The Center staff, in consultation with an interdisciplinary working group (consisting of scientists that are representative of our stakeholders), will develop written recommendations to be presented for review and comment to health disparity advocacy groups and other health professional groups</li> </ul>	FY03	
<ul style="list-style-type: none"> <li>Develop a review mechanism so the Advisory Council and Community Representatives can judge the relevance and appropriateness of priorities</li> </ul>	FY03	
<ul style="list-style-type: none"> <li>Analyze comments from health disparity advocacy groups and other health professional groups on the recommendations provided and forward analysis and recommendations to the NCMHD advisory group for prioritization</li> </ul>	FY03 and FY04	
<ul style="list-style-type: none"> <li>Develop knowledge management plan for research               <ul style="list-style-type: none"> <li>Inventory current and past minority health and other health disparity research conducted and supported by the NIH and other agencies and foundations. (Potential partnership with NLM)</li> </ul> </li> </ul>	FY03	
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Identify gaps in existing body of research</li> </ul> </li> </ul>	FY03	
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Share information with other ICs</li> </ul> </li> </ul>	FY03-FY06	
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Fund research to fill those gaps</li> </ul> </li> </ul>	FY03-FY06	
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Annual update and review information management tool</li> </ul> </li> </ul>	FY03-FY06	
<ul style="list-style-type: none"> <li>Explore with the Advisory Council, other experts and stakeholders, the establishment of long-term health disparity reduction goals from which interim goals can be developed. (For example, "Our goal is to reduce the disparity gap in the prevalence of Type II diabetes in African Americans by X percent in 20 years)</li> </ul>	FY03-FY04	

### 1.1.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
▪ Extent to which the NCMHD research portfolio reflects research priorities as measured by the percent of funding that is directed towards established priorities	Base	30%	45%	65%	85%
▪ Identify and respond to new priorities, unexpected concerns and gaps as measured by the percent of budget reserved for these contingencies	Base	15%	15%	15%	15%
▪ Usefulness of knowledge management tool as measured by the number of inquiries/hits to the research inventory database that is part knowledge management tool (objective 2.3)			Base	15%	25%

\* Targets subject to change based on collection of baseline data. Percentages refer to increase over base year unless otherwise stated. Base year is deferred to out years when significant "ramp-up" time is expected.

### 1.1.3 Timeline

- Noted in the Action Plan

### 1.1.4 Outcome Measures

- An annually updated listing of research priorities, emerging concerns, and a judgment of their relevance. (The Advisory Council and Community representatives will assist in making judgments)
- Determine the feasibility of defining long-term health disparity reduction goals in key diseases and conditions by FY04

## 1.2 Research Objective Two: Conduct and support research to better define the health disparity research domain, and develop research tools that are population-specific

While it is important to set research priorities, it is clear that certain fundamental areas of investigation must be explored to enable minority health and other health disparity research to proceed. This research will assist in identifying population-specific issues and in developing research tools, such as survey instruments for further research. Moreover, this research will also be helpful in setting future priorities.



### 1.2.1 Action Plan and Milestones

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Support research using cutting-edge and emerging technologies to identify biological and other risk factors for disease among significant sub-cohorts of health disparity populations (i.e., Hispanic/Latin divided into Dominican, Puerto Rican, Mexican, Cuban, etc.)</li> </ul>	Late FY02- FY03	
<ul style="list-style-type: none"> <li>Fund research to develop validated survey instruments for specific minority populations and sub-cohorts that are relevant to the diseases, conditions and behaviors known to be the most significant (heart disease and risks, diabetes and risks, cancer and risks, HIV and risks, etc) SBIR mechanisms will be included in this endeavor.               <ul style="list-style-type: none"> <li>Award first grants</li> <li>First tools available</li> <li>First tools available for public use available.</li> </ul> </li> </ul>	Late FY03  Late FY03 FY05 FY06	
<ul style="list-style-type: none"> <li>Explore the feasibility of a longitudinal or “Framingham-like Study” for racial and ethnic minority populations that focuses, not just on heart disease, but a spectrum of illnesses. This multi-disease approach can provide data for multiple ICs and therefore is a cost efficient way of exploring the epidemiology and evolution of disease in health disparity populations.               <ul style="list-style-type: none"> <li>Background exploration of feasibility and cost</li> <li>Ascertain level of interest/commitment of other ICs</li> <li>Develop candidate populations and sites</li> <li>Create more specific budget and examine impact on resources</li> <li>Propose 1 –3 pilot sites</li> <li>Commence enrollment</li> </ul> </li> </ul>	FY03 FY03 FY03 FY04 FY04 FY05 –FY06	

### 1.2.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
<ul style="list-style-type: none"> <li>Scientific publications that report on the progress and results of the research</li> </ul>		Base	5%	15%	25%
<ul style="list-style-type: none"> <li>Increased support of longitudinal and epidemiological studies as measured by the number of RFAs developed by disease segment</li> </ul>		Base	5%	10%	20%
<ul style="list-style-type: none"> <li>Increase in utilization of the tools developed as measured by the extent to which the original paper in which they were presented is cited in the literature.</li> </ul>				Base	5%

\* Targets subject to change based on collection of baseline data. Percentages refer to increase over base year unless otherwise stated. Base year is deferred to out years when significant "ramp-up" time is expected.

### 1.2.3 Timeline

- Indicated in the Action Plan

### 1.2.4 Outcome Measures

- Final feasibility assessment of Framingham-like studies described above.
- Assessment by an external panel of experts and community representatives regarding the attempt to better define the disparity research domain and develop research tools that are population specific as judged by the following criteria:
  - Quality of research
  - Relevance of research
  - Extent to which research "leads the field"
  - The usefulness of tools developed (see third performance measure)

## 1.3 Research Objective Three: Conduct and support research that may have a direct impact on closing health disparities

The goal of the NCMHD and the NIH is not merely to better define the nature of health disparities, but to understand root causes and actually to close the "disparity gap". Intervention studies, which examine the efficacy of specific interventions, strategies, and methods to improve the health of minorities and other health disparity populations, are a vital component of the overall research strategy. These intervention studies may involve biomedical, behavioral, pharmaceutical social sciences, or health care delivery innovations. Through such efforts, the NCMHD will be able to demonstrate what is effective in improving health in disparity cohorts. In many cases it may be possible generalize to broader minority and other health disparity populations. In these cases the intermediate outcome measures may be the actual degree to which certain interventions may be projected to close a disparity gap if they could be implemented in the broader population.

### 1.3.1 Action Plan and Milestones

Action Plan:	Milestones	
	Target	Achieved
▪ Conduct and/or support intervention trials that test the efficacy of different strategies to close the disparity gap in different populations afflicted with different disorders.	FY3-FY06	
○ Based on priorities established as described in Objective 1.1 target diseases and populations	FY03-FY06	
○ Identify candidate "interventions"	FY03-FY06	
○ Publish RFAs	FY03-FY06	

### 1.3.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
▪ Increase in the number of targeted intervention studies		Base	5%	10%	20%
▪ Number of grant awards made to private community based organizations		Base	5%	10%	25%
▪ Scientific publications that report the progress and results of the intervention trials		Base	5%	10%	25%

\* Targets subject to change based on collection of baseline data. Percentages refer to increase over base year unless otherwise stated. Base year is deferred to out years when significant "ramp-up" time is expected.

### 1.3.3 Timeline

- Noted in Action Plan

### 1.3.4 Outcome Measures

- Extent to which long-term (20 yr) and interim goals (5 yr) for the reduction of specific disparities are met. (See Objective 1.1)
- Health disparity reductions in experimental cohorts compared to control groups
- Performance as Measured by Expert Review
- Yearly assessment of the intervention research program by an external panel of experts and community representatives using the following criteria:
  - Quality of research
  - Relevance of research
  - Extent to which research "leads the field"

## 1.4 Research Objective Four: Develop methodologies to effectively conduct outreach and measure the impact of outreach efforts

The fruits of research will not be fully realized if they are not communicated to racial and ethnic minorities and other health disparity communities. Furthermore, the nuances of effective communication with minority and health disparity communities are a legitimate area of scholarly investigation. For instance, reaching out to Dominican women regarding breast cancer screening may require a different approach than reaching out to Mexican or Native American women. However, outreach is not merely about effective communication and understanding; it is often about changing behavior. Research that measures the efficacy of outreach in changing behavior of defined populations is important in establishing "best practices."

### 1.4.1 Action Plan and Milestones

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Conduct and support research to define methods of communication that are most effective in the influencing behavior and affecting health status</li> </ul>	FY04 -FY06	
<ul style="list-style-type: none"> <li>Conduct and support research to develop tools and methods for measuring the impact of specific outreach initiatives in altering behavior</li> </ul>	FY04-FY06	
<ul style="list-style-type: none"> <li>Conduct and support research that develops and validates effective tools and methodologies for communicating with defined populations</li> </ul>	FY04-FY06	

### 1.4.2 Performance Measures

Performance Measure	Targets*				
	FY02	FY03	FY04	FY05	FY06
<ul style="list-style-type: none"> <li>Increase in the number of validated tools</li> </ul>			Base	5%	10%
<ul style="list-style-type: none"> <li>Scientific publications that report progress and results with respect to establishing best communications practices</li> </ul>		Base	5%	10%	25%

\*Targets subject to change based on collection of baseline data. Percentages refer to increase over base year unless otherwise stated. Base year is deferred to out years when significant "ramp-up" time is expected.

### 1.4.3 Timeline

- Noted in Action Plan

### 1.4.4 Outcome Measures

- The extent to which the NCMHD and other ICs use these tools and approaches in their outreach effort. The goal is that 50% of these approaches are used in NIH related projects within 5 years of their development.
- Performance as Measured by Expert Review
- Yearly assessment of the intervention research program by an external panel of experts and community representatives using the following criteria:
  - Quality of research
  - Relevance of research
  - Extent to which research "leads the field"

## 2.0 AREAS OF EMPHASIS: RESEARCH INFRASTRUCTURE

Building capacity for minority health and other health disparities research is a high priority for the Center. Accordingly, NCMHD is using a portion of its resources to increase research infrastructure at strategically located institutions committed to addressing and ultimately eliminating disparities in health status. Three key programs are the nucleus of the Center's research infrastructure activities and will be NCMHD's highest priority for developing research infrastructure: 1) the Endowment Program for Section 736 Institutions, the Centers of Excellence in Partnerships for Community Outreach, 2) Research on Health Disparities and Training (Project EXPORT), and 3) the Loan Repayment Program for Health Disparities Research (HDR-LRP). The NIH director also requested that the NCMHD develop and implement the Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds (ECR-LRP). The HDR-LRP and the ECR-LRP emphasize recruiting racial and ethnic minorities and other underrepresented individuals to conduct research and will promote a diverse workforce that is able to address society's diverse needs. The programs also ensure the availability of a cadre of clinical researchers that understand the issues and problems associated with disparities in health status.

Overall, the NCMHD programs highlight NIH's commitment to ensuring that the highest quality research, research capacity, and outreach are brought to bear in addressing health disparities throughout the country. As part of the research infrastructure area of emphasis, the NCMHD will examine ongoing efforts developed under the auspice of ORMH and identify key gaps in minority health and other health disparity research infrastructure. In particular, the NCMHD will take the lead in developing a set of tools to be used throughout the research community to collect and analyze epidemiologic and demographic data on racial and ethnic minority and other health disparity populations.

### **2.1 Research Capacity Objective One: Develop a cadre of researchers with expertise in minority health and other health disparities research**

P.L. 106-525 also mandated that the NCMHD develop a vehicle for increasing the number of racial and ethnic minority researchers in the biomedical and behavioral field and increase the number of researchers conducting minority health and other health disparities research. To carry out this effort, the NCMHD will develop and implement two distinct extramural loan repayment programs:

- Loan Repayment Program for Health Disparities Research (HDR-LRP)
- Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds (ECR-LRP)

The HDR-LRP is designed to increase the number of highly qualified health professionals in research careers focused on health disparities. The focus of the ECR-LRP is to increase the participation of highly qualified health professionals from disadvantaged backgrounds in clinical research careers. To develop synergies between the NCMHD programs and ensure emphasis is placed on minority health and other health disparities research efforts, the NCMHD will work to establish links between the LRPs (HDR-LRP and ECR-LRP) and the NCMHD research priorities.

### 2.1.1 Loan Repayment Program for Health Disparities Research (HDR-LRP)

The HDR-LRP program seeks to recruit and retain highly qualified health professionals in research careers that focus on minority health disparities research or research related to the medically underserved. Upon acceptance into the program, participants are obligated to conduct a minimum of two years of basic, clinical, or behavioral research. In return for the participant's service, NCMHD will make direct payments to their lenders toward their outstanding educational loan debt. Pursuant to P.L. 106-525, at least 50 percent of the awards will be made to individuals from health disparity populations.

#### 2.1.1.1 Action Plan and Milestones

Because this is a newly created program, the NCMHD must undertake a number of actions to ensure the program is as effective and efficient as possible.

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Identify and review best practices from well established loan programs throughout the federal government and the private sector               <ul style="list-style-type: none"> <li>Identify efficient application distribution systems (e.g., via web-based solutions)</li> <li>Determine best approach for reviewing loan applications</li> </ul> </li> </ul>	November 2001	X
<ul style="list-style-type: none"> <li>Promote the HDR-LRP throughout the biomedical and behavioral, research, educational and minority and medically underserved communities.</li> </ul>	March FY02	
<ul style="list-style-type: none"> <li>Distribute applications</li> </ul>	July FY02	
<ul style="list-style-type: none"> <li>Review loan applications</li> </ul>	August FY02	
<ul style="list-style-type: none"> <li>Process loan repayments</li> </ul>	August-September FY02	
<ul style="list-style-type: none"> <li>Make awards</li> </ul>	September FY02	
<ul style="list-style-type: none"> <li>Analyze feasibility of developing a survey to identify continuous improvement opportunities at the end of each loan repayment cycle</li> </ul>	FY03	

#### 2.1.1.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
<ul style="list-style-type: none"> <li>The number of applicants for the LRP (Base = 75)</li> </ul>	175	250	300	350	400
<ul style="list-style-type: none"> <li>Number of LRP recipients who publish peer reviewed articles</li> </ul>	75	100	125	150	175
<ul style="list-style-type: none"> <li>Assure that a significant number of LRP applicants are researchers in training or have recently commenced their research careers</li> </ul>	30%	50%	50%	50%	50%
<ul style="list-style-type: none"> <li>Assure that a significant number of LRP awardees are from health disparities populations</li> </ul>	50%	50%	50%	50%	50%
<ul style="list-style-type: none"> <li>Percent of awardees in their 2<sup>nd</sup> or 3<sup>rd</sup> year of the program attend educational or technical assistance workshops, seminars and other educational mechanisms and encouraged to apply for small grant support</li> </ul>		Base (20% of Awards)	25%	30%	35%
<ul style="list-style-type: none"> <li>Percent of LRP recipients who participate in community outreach efforts</li> </ul>	95%	95%	95%	95%	95%

\* Targets subject to change based on collection of baseline data

### **2.1.1.3 Timeline**

- The NCMHD began administering loan repayments in FY01. The HDR-LRP is congressionally authorized through FY06. Incremental milestones are listed above in the Action Plan and Milestones table.

### **2.1.1.4 Outcome Measures**

- 20% of awardees are still conducting minority health disparity research 5 years after their award.
- 20% of minority awardees are still conducting minority health disparity research 5 years after their award.

### **2.1.2.1 Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds (ECR-LRP)**

The ECR-LRP program provides an incentive for health professionals from disadvantaged backgrounds to conduct clinical research. The emphasis on “clinical research” and on individuals from “disadvantaged” backgrounds is consistent with the draft trans-NIH Strategic Plan objectives of building a culturally competent cadre of clinical investigators. The growing gap in income between the rich and poor; inequities in health related to race, poverty, substandard housing, lack of employment opportunities; and an increasing perception of hopelessness and powerlessness among marginalized populations highlight the need for the involvement of a cadre of culturally competent physician scientists in clinical research. Such a cadre of clinical investigators not only have the potential of impacting the medical processes within their communities, but they can also engage in and promote the development of clinical research programs that reflect an understanding of the variety of issues and problems associated with health status.

An “individual from a disadvantaged background” is one who: (1) comes from an environment that inhibited individuals from obtaining the knowledge, skills and abilities required to enroll in and graduate from a health professions school; or (2) comes from a family with an annual income below a level based on low-income thresholds according to family size as published by the U.S. Bureau of Census and adjusted by the Secretary of DHHS for use in all health professional programs. Current financial need is not sufficient to classify an individual as being from a disadvantaged background.

In order to be eligible for the program, the candidate must meet the criteria stated above, as well as meet other minimum requirements established by the NIH and the NCMHD. Upon acceptance into the program, candidates are obligated to conduct a minimum of two years of clinical research. In return for the participants’ service, the NCMHD will make direct payments to the participants’ lenders for qualified education loan debt.

### **2.1.2.1 Action Plan and Milestones**

Because this is a newly created program, the NCMHD must undertake a number of actions to ensure the program is as effective and efficient as possible.

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Identify and review best practices from well established loan programs throughout the federal government and the private sector. <ul style="list-style-type: none"> <li>Identify efficient application distribution systems (e.g., via web-based solutions)</li> <li>Determine best approach for reviewing loan applications</li> </ul> </li> </ul>	November 2001	X
<ul style="list-style-type: none"> <li>Promote the ECR-LRP throughout the biomedical, research, educational and minority communities.</li> </ul>	March FY02	
<ul style="list-style-type: none"> <li>Distribute applications</li> </ul>	July FY02	
<ul style="list-style-type: none"> <li>Review loan applications</li> </ul>	August FY02	
<ul style="list-style-type: none"> <li>Process loan repayments</li> </ul>	August- September FY02	
<ul style="list-style-type: none"> <li>Make awards</li> </ul>	September FY02	
<ul style="list-style-type: none"> <li>Analyze feasibility of developing a survey to identify continuous improvement opportunities at the end of each loan repayment cycle.</li> </ul>	FY03	

### 2.1.2.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
<ul style="list-style-type: none"> <li>The number of applicants for the LRP</li> </ul>	50	75	100	125	150
<ul style="list-style-type: none"> <li>Number of LRP recipients who publish peer reviewed articles</li> </ul>	75	100	125	150	175
<ul style="list-style-type: none"> <li>Assure that a significant percent of LRP applicants are researchers in training or have recently commenced their research careers</li> </ul>	30%	50%	50%	50%	50%
<ul style="list-style-type: none"> <li>Assure that a significant percent of LRP awardees are from health disparities populations</li> </ul>	50%	50%	50%	50%	50%
<ul style="list-style-type: none"> <li>Percent of awardees in their 2<sup>nd</sup> or 3<sup>rd</sup> year of the program attend educational or technical assistance workshops, seminars and other educational mechanisms and encouraged to apply for small grant support</li> </ul>		Base (20% of Awards)	25%	30%	35%
<ul style="list-style-type: none"> <li>Percent of LRP recipients who participate in community outreach efforts</li> </ul>	Base	95%	95%	95%	95%

\* Targets subject to change based on collection of baseline data

### 2.1.2.3 Timeline

- The NCMHD began administering loan repayments in FY01, and plans to continue the LRP indefinitely. Incremental milestones are listed above in the Action Plan and Milestones table.

### 2.1.2.4 Outcome Measures

- A 20% increase in the number of researchers from disadvantaged backgrounds pursuing careers in clinical research over five years.



## **2.2 Research Capacity Objective Two: Promote and support research capacity building activities in racial and ethnic minority and medically underserved communities.**

In passing P.L. 106-525, the U.S. Congress recognized the need to increase the facilities and workforce supporting and conducting minority health and health disparity research. To meet this need, the U.S. Congress has given the NCMHD extramural funding capabilities and the statutory authority to promote and support research capacity building activities through two programs:

- The Centers of EXcellence in Partnerships for Community Outreach, Research on Health Disparities and Training (Project EXPORT)
- An Endowment Program for Section 736 Institutions

### **2.2.1.1 Action Plan: The Centers of Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training (Project EXPORT)**

Pursuant to the Public Law, the NCMHD will develop and implement a network of Centers of Excellence in partnerships for Community Outreach, Research on Health Disparities and Training. The Project EXPORT COEs will be established at academic institutions with a significant number of students from racial and ethnic minority and other health disparity populations.

These Centers will 1) promote the conduct of minority health and/or health disparity research aimed at reducing disparities in health status; 2) promote the participation of members of health disparity groups in biomedical and behavioral research and prevention and intervention activities through education and training; and 3) build research capacity in minority-serving institutions. In addition, P.L. 106-525 gives the NCMHD Director the authority to allow these centers to expend a portion of their award to establish a health disparities research endowment. During the current fiscal year, NCMHD will release an RFA notifying institutions of the opportunity to compete for program funds. Because the law provides for partnerships between “designated” and non-designated institutions, providing opportunities for exploratory planning grants will allow these institutions sufficient time and resources to plan and establish synergistic and effective partnership models that capitalize on their respective strengths for carrying out the mission of the NCMHD Project EXPORT COEs. The exploratory grant mechanism will be a one-time award to support activities (e.g. planning meetings, travel, institutional and community assessments, staff recruitment activities) aimed at exploring the feasibility of establishing NCMHD Project EXPORT Centers of Excellence. Planning strategies for centers may focus on a specific research theme (e.g., diagnosis, therapy, or epidemiology of diabetes, cardiovascular disease, cancer, etc.) or integrate a broad spectrum of research to include basic, clinical, prevention, and population sciences research. To become eligible for these grants, institutions must have:

- A significant number of members of minority health disparity populations or other health disparity populations enrolled as students in the institution (including individuals accepted for enrollment)
- Been effective in assisting its students to complete the program or training and receive a degree
- Made significant efforts to recruit minority students to enroll in and graduate from the institution, which may include providing means-tested scholarships or other financial assistance as appropriate
- Made significant recruitment efforts to increase the number of minority or other members of health disparity populations serving in faculty or administrative positions at the institution

Eligible institutions that meet specified secondary qualifications will also be encouraged to apply for funding to ensure the participation of institutions located in the geographic regions experiencing the greatest disparities in health status.

The NCMHD's Project EXPORT will provide sustainable core support for minority health and other health disparities research programs as well as provide support for research infrastructure development. Additionally, as part of the guidelines for receiving a grant to establish Centers of Excellence, institutions must develop and measure outreach mechanisms to educate and inform their constituents.

Because this is a newly created program, the NCMHD must undertake a number of actions to ensure the program is as effective and efficient as possible.

<b>Action Plan:</b>	<b>Milestones</b>	
	<b>Target</b>	<b>Achieved</b>
<ul style="list-style-type: none"> <li>▪ Promote awareness of and increase understanding of the NCMHD Project EXPORT Centers of Excellence (e.g., Technical Assistance Workshops, Request for Applications, NCMHD Website)</li> </ul>	January FY03	
<ul style="list-style-type: none"> <li>▪ Identify and implement best practices from established public and private grant-making organizations (e.g., Grant making, Peer Review Process, Program Review/Evaluation)</li> </ul>	FY02	
<ul style="list-style-type: none"> <li>▪ Make awards</li> </ul>	End of FY02	
<ul style="list-style-type: none"> <li>▪ Monitor grantee performance including:               <ul style="list-style-type: none"> <li>○ Publication of scientific and technical articles about their research in peer review journals</li> <li>○ Recruitment and retention of minority scientists in the fields of biomedical and behavioral research at NCMHD Project EXPORT COEs</li> <li>○ Recruitment and retention of qualified individuals trained at institutions with NCMHD Project EXPORT COEs who are currently underrepresented in the scientific, technological, and engineering workforce in public and private sector organizations</li> <li>○ Use of endowment funds</li> </ul> </li> </ul>	Annually, due at end of each fiscal year	

### 2.2.1.2 Performance Measures

Performance Measures	Target*				
	FY02	FY03	FY04	FY05	FY06
▪ An increase in the number of applications for NIH research project grants being submitted by researchers from institutions with NCMHD Project EXPORT COEs		Base	15%	15%	20%
▪ An increase in the number of NIH research project grants awarded to researchers at institutions with NCMHD Project EXPORT COEs		Base	10%	10%	15%
▪ Percent increase in the number of minority research related articles published by individuals training or being trained at Project EXPORT COEs			Base	5%	10%
▪ Percent increase in the number of students trained at institutions with NCMHD Project EXPORT COEs who continue work in the field of minority health disparity research			Base	5%	10%
▪ Increase the number of basic and clinical researchers representative of minority and other health disparity populations		Base	10%	15%	20%
▪ Percent increase in the number of community based efforts established in association with an NCMHD Project EXPORT COE		Base	15%	20%	25%

\* Targets subject to change based on collection of baseline data

### 2.2.1.3 Timeline

- The NCMHD will begin the Project EXPORT COE program in FY02, and plans to continue it indefinitely. Incremental milestones are listed above in the Action Plan and Milestones table.

### 2.2.1.4 Outcome Measures

- Increase the number of capital improvement projects, over five years, and itemize them in the annual report

#### 2.2.2.1 Action Plan: NCMHD Endowment Program for Section 736 Institutions

The NCMHD 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 determined that the establishment of federally supported endowment funds is an appropriate method of building research and training capacity in institutions that make significant investments in the education and training of underrepresented minority and socio-economically disadvantaged individuals.

Through the Endowment Program, the NCMHD will help to:

- Address the disparities in the burden of illness and death experienced by African Americans, Hispanics, Native Americans, Alaska Natives, Asian Pacific Islanders and other underserved populations as compared to the Nation as a whole

- Expand or add programs that effectively overcome educational and financial resource barriers to promote a diverse and strong scientific, technological and engineering workforce for the 21st century
- Work in concert with the private and nonprofit sectors to emphasize the recruitment and retention of qualified individuals from ethnic and gender groups that are currently underrepresented in the scientific, technological and engineering workforce
- Assist in the recruitment of more minority scientists in the fields of biomedical and behavioral research and other areas of the scientific, technological and engineering workforce
  - The objective of the Endowment Program is to facilitate a decrease in reliance on governmental financial support and encourage reliance on endowments and private sources. Eligible institutions include only those institutions with corporate or total institutional endowment assets of less than half the national average for section 736 institutions that conduct similar biomedical research or training of health professionals. Regarding partnerships, collaborating institutions that meet these criteria may independently apply for endowment support.

Additionally, as part of the guidelines for receiving an endowment, institutions must develop and measure outreach mechanisms to educate and inform their constituents. The NCMHD will monitor endowments throughout the life of the award. Because this is a newly created program, the NCMHD must undertake a number of actions to ensure the program is as effective and efficient as possible.

Action Plan:	Milestones	
	Target	Achieved
▪ Identify and implement best practices from established public and private grant-making organizations (e.g., Grant making, Peer Review Process, Program Review/Evaluation)	FY02	
▪ Make endowment awards	End of FY02	
▪ Monitor grantee performance including: <ul style="list-style-type: none"> <li>○ Publication of scientific and technical articles about their research in peer review journals</li> <li>○ Recruitment and retention of minority scientists in the fields of biomedical and behavioral research at Section 736 institutions</li> <li>○ Recruitment and retention of qualified individuals trained at Section 736 institutions who are currently underrepresented in the scientific, technological, and engineering workforce in public and private sector organizations</li> <li>○ Use of endowment funds</li> </ul>	Annually, due at end of each fiscal year	

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Promote awareness of and increase understanding of the NCMHD Endowment Program among Section 736 institutions with currently funded Programs of Excellence in Health Professions Education through Technical Assistance Workshops, Request for Applications, and the NCMHD Website</li> </ul>	FY03	

### 2.2.2.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
<ul style="list-style-type: none"> <li>Percent increase in the number of applications for competitive research awards being submitted by researchers from NCMHD-endowed Section 736 institutions</li> </ul>		Base	10%	15%	20%
<ul style="list-style-type: none"> <li>Percent increase in the number of NIH research project grants awarded to researchers at NCMHD-endowed Section 736 institutions</li> </ul>		Base	5%	10%	15%
<ul style="list-style-type: none"> <li>Percent increase in the number of minority research related articles published in peer reviewed journals by individuals training or being trained through endowment funding</li> </ul>			Base	5%	10%
<ul style="list-style-type: none"> <li>An increase in the number/percent of students trained at NCMHD endowed institutions who continue work in the fields of minority health and health disparity research</li> </ul>			Base	5%	10%

\* Targets subject to change based on collection of baseline data (Baseline data comprises the data collected in the Endowment Program's first year.)

### 2.2.2.3 Timeline

- NCMHD began the Endowment program in FY01. Incremental milestones are listed above in the Action Plan and Performance Milestones table.

### 2.2.2.4 Outcome Measures

- Increase the number of capital improvement projects and itemize them in the annual report
- A 50% increase over five years in the number of researchers focusing on minority health and health disparity research as a result of graduating from or teaching at a section 736 institution with an NCMHD endowment
- A 30% increase over five years in articles published in research journals focusing on minority health disparities originating at Section 736 institutions that have an NCMHD endowment

## 2.3 Research Capacity Objective Three: Develop and refine research tools, survey instruments, and databases that are culturally sensitive, culturally competent and specifically designed for minority and other health disparity populations

As the coordinator of minority health and health disparity activities and information, the NCMHD will implement a knowledge repository database, or interconnected series of databases, to facilitate the retrieval, analysis and dissemination of minority health and other health disparity research, infrastructure and outreach information. A sophisticated mechanism of information sharing, leveraging the newest technologies, must be established to ensure all stakeholders can benefit from the multiple sources of information.

To this end, the NCMHD will improve the infrastructure for collecting and analyzing epidemiological and demographic data on minority populations by developing and refining research tools, survey instruments, and databases. This knowledge repository must be culturally sensitive, culturally competent, and specifically designed for minority and other health disparity populations. The NCMHD will also support efforts to improve the Surveillance, Epidemiology and End Results (SEER) data system at the National Cancer Institute (NCI).

### 2.3.1 Action Plan and Milestones

To lead the development of enhanced mechanisms for collecting and analyzing epidemiological and demographic data on minorities, the NCMHD will:

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Explore opportunities for partnerships with the private sector, particularly genomics and pharmaceutical companies, to develop better mechanisms to collect and analyze data on minorities' health and diseases of minorities and other populations.</li> </ul>	FY03	
<ul style="list-style-type: none"> <li>Encourage knowledge sharing and cross-disciplinary research between NIH Institutes and Centers, as well as the Center for Disease Control (CDC). This will include reviewing ongoing infrastructure development efforts funded by the NCMHD.</li> </ul>	FY03-FY06	
<ul style="list-style-type: none"> <li>Identify requirements to develop the most effective and efficient mechanisms of creating a data management solution to benefit research on three fronts:               <ul style="list-style-type: none"> <li>NCMHD Research</li> <li>Intramural Research (within NIH ICs)</li> <li>Extramural Research (NIH partnering institutions and Community Groups)</li> </ul> </li> </ul>	FY03	
<ul style="list-style-type: none"> <li>Standardize and improve record keeping on minority and ethnic groups and the underserved by states. SEER data system should improve and refine descriptors for minority groups to reflect the number of minority and ethnic groups and the diversity within minority populations.</li> </ul>	FY03-FY04	
<ul style="list-style-type: none"> <li>Examine the practices of institutions that have effective mechanisms of collecting data, developing research tools and survey instruments, and leveraging information among various studies.</li> </ul>	FY03	

### 2.3.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
▪ Percent increase of studies utilizing newly developed tools		Base	30%	40%	50%
▪ Increase in the number of tools		Base	20%	40%	60%

\* Targets subject to change based on collection of baseline data

### 2.3.3 Timeline

- NCMHD will begin this effort in FY02

### 2.3.4 Outcome Measures

- An improvement in methods for collection and dissemination of data and the promotion of surveillance studies with the development of data banks, databases, “registries” of information on minority populations

## 3.0 AREA OF EMPHASIS: OUTREACH

Effective community outreach is bi-directional. Listening is as important as informing. Consequently, the NCMHD is committed to creating communication channels that lend themselves to the interactive nature of effective outreach. Different communities require different modes of communication. The word "community" is used broadly here since the NCMHD must reach out, not only to constituent communities, but to the community of advocates, health professionals and institutions as well. Accordingly, the NCMHD divides its outreach efforts into three major objectives:

- Outreach to Communities and their Community Based Organizations
- Outreach to Health and Social Service Professionals
- Outreach to Health, Research and Social Service Institutions, Professional Organizations, and the Business Sector

In each of these categories the NCMHD may take on the role of partner, leader, or resource. The nature of that role defines the nature of the relationship, and consequently, the nature of communication and outreach required. However, the NCMHD is a new Center and before it can pursue the outreach objectives described above, it must create the institutional infrastructure to plan and lay the groundwork for the outreach effort.

### Laying the Groundwork for Effective Outreach

In reaching out to communities and stakeholders it is critical to convey a message that faithfully communicates the identity and mission of the organization. Therefore, it is important that the Center go through the necessary steps to establish its identity in order to create greater public understanding of the mission of the NCMHD. This will help develop unified thinking within the Center and its stakeholder community. The NCMHD must also develop a comprehensive communications strategy. This strategy will help identify the target audience, determine the communications objectives, design the message, manage the communications mix, and measure

the communication results. Developing an effective communications strategy, implementing the plan and developing the infrastructure to implement the plan is a significant undertaking. The NCMHD has begun the process of developing its branding approach, has created its website, and is actively developing its communications strategy.

In the process of building an outreach infrastructure, the Center will continue to reach out to communities, community-based organizations, and other stakeholders because it is vital that the Center have a solid understanding of the communications needs of those it serves. Those needs vary in urban and rural environments, and among different ethnic groups. In the process of gathering input the Center may use various means, from town hall meetings, focus groups and workshops, to larger conferences, surveys and ethnographic studies. Although this is a time consuming process, it is the essential foundation for an effective outreach program. The funding cycle and performance measures in this section reflect the necessary time required to gather this input and build the appropriate information foundation.

In measuring outreach performance we used both milestones tied to action plans and performance measures that capture improvements over time. The performance measures focus on two primary dimensions: 1) volume, or the number of groups and individuals touched; and 2) quality, or the efficacy of communications. In the case of volume, merely tallying up the number of leaflets distributed and similar gross measures are not satisfying measures. Where possible, we tried to emphasize capacity for volume - such as in the size of a database, or meaningful interactions – such as the number of inquiries to a database or website. In the case of quality, the best and simplest measure is to ask a random sample of users and stakeholders how we are performing communication efforts. The outcome measure in each outreach category is to establish a high quality, nationwide outreach network by a specified date.

### **3.1 Outreach Objective One: Outreach That Engages Communities and their Community- Based Organizations**

An understanding of affected communities drives minority health and other health disparity research priorities. The fruits of research will never be fully realized until they are communicated to these same communities and translated into practice. Therefore, developing a strategic relationship with community-based organizations is of the highest priority. However, developing and implementing an effective outreach effort is a daunting task. There are many people to reach and often they are among the most difficult to reach members of our society. Barriers of language, literacy, mobility, money, geography, vision and hearing, all conspire to thwart communication efforts. In order to succeed in this endeavor, the NCMHD will partner with multiple agencies and leverage existing channels – including individual health and social service providers. However, in many cases it will have to develop new methods and new channels to enhance the depth, breadth and efficacy of its outreach efforts. As noted in the "Research Area of Emphasis", some research resources will be devoted to developing innovative and effective means of outreach. The research will be leveraged in the outreach effort described in this section as the Center identifies and implements best practices.



### 3.1.1 Action Plan and Milestones

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Explore with the NCMHD Advisory Council and stakeholders the most appropriate means for establishing effective outreach to minority and underserved communities. (e.g., Tribal Consultation Plan)</li> </ul>	FY03	
<ul style="list-style-type: none"> <li>Continue to reach out to communities, community-based organizations and other stakeholders to collect input regarding their communications needs and the best methods of maintaining a communications relationship. This may include methods such as town hall meetings, workshops, focus groups, conferences, surveys and other studies. (This could also serve as an infrastructure for ongoing quality improvement and satisfaction measurement)</li> </ul>	FY02-FY06	
<ul style="list-style-type: none"> <li>Explore the feasibility of establishing a national database of effective and strategically located community based organizations, churches, and faith communities that may be marshaled in an outreach effort. The database should be part of the broader knowledge management effort and should have a Geographic Information Systems (GIS) component. This GIS component will permit pinpointing of specific outreach messages to well-defined areas of disparity. (This has significant overlap with the coordination function and the Infrastructure Area of Emphasis)</li> </ul>	FY03	
<ul style="list-style-type: none"> <li>As outreach focused research begins to reveal effective and innovative means of outreach, explore the feasibility of holding conferences to showcase that work and serve as a focal point of exchange with other scholars and practitioners working in this domain. (See Section 1.4)</li> </ul>	FY03 – FY06	

### 3.1.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
<ul style="list-style-type: none"> <li>Increase in volume of communications as measured by an increase in number of CBOs included in database and other indicators of volume</li> </ul>			Base	10%	20%
<ul style="list-style-type: none"> <li>Increase in satisfaction of CBOs with communications efforts as measured by surveys and other quantitative means</li> </ul>		Base	10%	15%	20%

\* Targets subject to change based on collection of baseline data. Percentages refer to increase over base year unless otherwise stated. Base year is deferred to out years when significant "ramp-up" time is expected.

### 3.1.3 Timeline

- As described in Action Plan

### 3.1.4 Outcome Measures

- An established communications network that provides research-based information and responds to the information needs of existing and future community-based organizations in all 50 states by the end of FY05.

## 3.2 Outreach Objective Two: Outreach That Engages Health and Social Service Professionals

Individual caregivers provide a vital link in the outreach chain. They have the opportunity to speak with patients and clients one-on-one in the context of a special relationship. It is extremely important to have a network that reaches these professionals, who in turn can share information with individuals in their care. In keeping with the principle of bi-directionality, health care providers must have the means to communicate with NCMHD so they can relay their concerns and provide their insights.

### 3.2.1 Action Plan and Milestones

Action Plan:	Milestones	
	Target	Achieved
▪ Explore the feasibility of creating a research database of scientific articles relevant to minority health and other health disparities that could be easily accessed by health care professionals. This would be analogous to a Medline service and could be done in partnership with NLM.	FY02	
▪ Explore with the NCMHD Advisory Council the creation of minority health and other health disparity curricula that can be adapted and used by schools of nursing, medicine and social work. In a parallel effort, CME courses may be created for practicing professionals.	FY03	
▪ Explore with the NCMHD Advisory Council the creation of a textbook on minority health and health disparities that can be used in conjunction with the curricula cited above.	FY03	
▪ Explore with the NCMHD Advisory Council the creation of Journal of Minority Health and Health Disparities that can not only be used as a venue for publication, but a tool of communication.	FY03	

### 3.2.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
▪ Increase in volume of communications to individual professionals as measured by an increased number of hits/page views/ inquiries to literature database and other indicators of communication volume			Base	10%	20%

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
<ul style="list-style-type: none"> <li>Increase in satisfaction of professionals with regard to communications as measured by surveys and other quantitative means.</li> </ul>			Base	10%	15%

\* Targets subject to change based on collection of baseline data. Percentages refer to increase over base year unless otherwise stated. Base year is deferred to out years when significant "ramp-up" time is expected.

### 3.2.3 Timeline

- As described in Action Plan

### 3.2.3 Outcome Measures

- An established communications network that provides research-based information and responds to the information needs of health and social service professionals in all 50 states by the end of FY05.

## 3.3 Outreach Objective Three: Outreach That Engages Health, Research and Social Service Institutions, Professional Organizations, and the Business Sector

Health care and social service institutions often play an important role in the lives of health disparity populations. Because of their presence in the community as both providers and employers, and because they often have pre-existing networks, it is important to leverage their capabilities in outreach efforts. The other NIH Institutes and Centers all have an outreach infrastructure that could be coordinated and leveraged in the outreach effort. Enhanced communication between research institutions, such as the various NIH Institutes and Centers, would enhance the health disparity research endeavor and is also a legitimate objective of the outreach function. The for-profit sector is an important part of the institutional outreach effort. Large employers and small businesses play an important role in the life of a community, and will require special outreach strategies to enlist them in the health disparity effort.

### 3.3.1 Action Plan and Milestones

Action Plan:	Milestones	
	Target	Achieved
<ul style="list-style-type: none"> <li>Explore acquisition or establishment of a database of hospitals, clinics and other key institutions in minority/health disparity communities. Database should include the names of key information/public relation's staff, and have a strong GIS component. These institutions could be leveraged in disseminating information, developing behavior change programs, and in recruiting research subjects. (This has significant overlap with Infrastructure Area of Emphasis and related Objectives)</li> </ul>	FY03	
<ul style="list-style-type: none"> <li>Identify and consider reaching out to other institutions and systems that may not be traditionally thought of in this effort such as state and federal prison systems; the VA Hospital</li> </ul>	FY03	

Action Plan:	Milestones	
	Target	Achieved
system; large employers, small businesses, HMOs and Health Insurance Companies active in minority and health disparity communities. These may be included in the database		
<ul style="list-style-type: none"> <li>Create relationships and collaborate with other Federal agencies, including other Institutes and Centers, who may wish to reach the same populations. The messages of different organizations need to be coordinated and consistent. The NCMHD can play a role in coordinating messages so that the database and the community-based partners are used most efficiently and effectively.</li> </ul>	FY04	
<ul style="list-style-type: none"> <li>Identify best practice outreach tools and techniques among the other ICs</li> </ul>	FY03	
<ul style="list-style-type: none"> <li>Require strategically located Centers of Excellence award recipients to take a leadership role in coordinating and leading outreach and information dissemination in a specified geographic area.</li> </ul>	FY02	X

### 3.3.2 Performance Measures

Performance Measures	Targets*				
	FY02	FY03	FY04	FY05	FY06
<ul style="list-style-type: none"> <li>Increase in volume of communications to institutional partners as measured by an increase in the size of the database and other indicators of volume</li> </ul>		Base	10%	20%	30%
<ul style="list-style-type: none"> <li>Increase in satisfaction of institutions with regard to communications as measured by surveys and other quantitative means</li> </ul>		Base	20%	40%	50%

\* Targets subject to change based on collection of baseline data. Percentages refer to increase over base year unless otherwise stated. Base year is deferred to out years when significant "ramp-up" time is expected.

### 3.3.3 Timeline

- As described in Action Plan

### 3.3.4 Outcome Measures

- An established outreach network that provides research-based information and responds to the information needs of health, social service and other institutions in all 50 states by the end of FY05.

NCMHD Health Disparities Budget  
(Dollars in Millions)

Institute / Center	FY 2002			FY 2003		
	Research	Infrastructure	Outreach	Research	Infrastructure	Outreach
NCMHD	\$48.90	\$98.70	\$2.30	\$52.00	\$122.80	\$3.70