

**U.S. Department of Health and Human Services (HHS)
National Institutes of Health (NIH)
National Center on Minority Health and Health Disparities (NCMHD)
National Advisory Council on Minority Health and Health Disparities (NACMHD)**

**Marriott Bethesda – Pooks Hill
5151 Pooks Hill Road
Bethesda, Maryland
June 23, 2009
8:00 a.m.–5:00 p.m.
Meeting Minutes**

Council Members Present

John Ruffin, Ph.D., Director, NCMHD; Chair, NACMHD
Jeffrey A. Henderson, M.D., M.P.H., Chair-Designee
Mario De La Rosa, Ph.D.
Mona N. Fouad, M.D., M.P.H.
Faye A. Gary, R.N., E.D.D.
Alvin E. Headen, Jr., Ph.D.
Steven R. Lopez, Ph.D.
Stephen A. Smith, M.B.A.
Maria L. Soto-Greene, M.D.
José Szapocznik, Ph.D.
Luther S. Williams, Ph.D.

Ex Officio Members

Christine A. Bachrach, Ph.D.
Gary Martin, D.D.S.

Absent Council and Ex-Officio Members

Paula Braveman, Ph.D.
Michael Fine, M.D., M.Sc.
Nilda Peragallo, Dr. PH, RN, FAAN
Brian D. Smedley, Ph.D.
Josh R. Valdez, D.B.A.

Ad Hoc Member

Hilton M. Hudson II, M.D., FACS
Wayne J. Riley, M.D., M.P.H., M.B.A., MACP

Presenters

Carolyn Clancy, M.D.
Christine Daley, Ph.D.
Terris King, M.S.
Mr. Thomas Edward Smith
Debra Wallace, Ph.D.

Deputy Director, NCMHD

Joyce A. Hunter, Ph.D.

Executive Secretary

Ms. Donna A. Brooks

CLOSED SESSION

The first portion of the meeting was closed to the public in accordance with provisions set forth in Sections 552b(c)(4) and 552b(c)(6), Title 5, U.S.C., and Section 10(d) of the Federal Advisory Committee Act, as amended, U.S.C. Appendix 2.

Executive Secretary Donna A. Brooks called the meeting to order at 7:57 a.m. She then turned proceedings over to NCMHD Director and NACMHD Chair, John Ruffin, Ph.D. Dr. Ruffin presided, and Jeffrey Henderson served as Chair-designee to facilitate the meeting.

The Council considered 37 applications requesting an estimated \$55,819,352 in total costs. Those that were noncompetitive, unscored, or not recommended for future consideration by the scientific review groups were not considered by the Council. Voting en bloc, the Council concurred with the first-level peer review of the applications made for Centers of Excellence grants (P60s) and the applications made for the Research Endowment Program. The Council also unanimously concurred with the first-level peer review of the Disparities in Research and Education Advancing our Mission (DREAM) program (K-22s), Conference grants (R13s), the Small Business Innovation Research (SBIR) and the Small Business Technology Transfer Research (STTR) programs.

Ms. Brooks adjourned the Closed Session at 9:27 a.m.

OPEN SESSION

CALL TO ORDER AND WELCOME

Ms. Brooks called the Open Session to order at 9:45 a.m.

OPENING REMARKS & INTRODUCTIONS

Dr. Ruffin welcomed participants to the Open Session of the 21st NACMHD meeting and then provided the following opening remarks.

He reminded the group about the American Recovery and Reinvestment Act of 2009 (ARRA), signed by President Obama, and reported on the flurry of activities at the NIH to expend the funds consistent with the law. There are relatively short timeframes for expenditure of ARRA funds, and increased transparency and accountability requirements will add to the workload around the NIH including that of the NCMHD staff and the Advisory Council in an effort to make ARRA awards by September 2009.

Dr. Ruffin announced the official appointment of four new Council members: Drs. Mona Fouad, Stephen Smith, Jose Szapocznik, as well as Paula Braveman who could not attend the meeting. Dr. Wayne Riley was also acknowledged as an incoming member, awaiting clearance of all official paperwork. Dr. Ruffin also recognized Dr. Hilton M. Hudson II, as an Ad Hoc member to the Council.

Dr. Ruffin then introduced new and ad-hoc members:

Dr. Mona Fouad is Director of the Minority Health and Research Center, and Professor in the Division of Preventive Medicine, at the University of Alabama at Birmingham.

Dr. Fouad is Principal Investigator (PI) on numerous Federal grants and co-PI on many others designed primarily to improve health and to prevent disease for minorities. Many of her studies rely heavily on community participation. She has worked with NCMHD to develop its Community-Based Participatory Research (CBPR) Program.

Mr. Stephen Smith is President of the Indiana Health Care Association, based in Indianapolis, which advocates for more than 300 nursing homes and long-term care facilities in the state. Mr. Stephen Smith has more than 18 years of experience in the field.

Dr. Jose Szapocznik is Professor and Chair, Department of Epidemiology and Public Health, and Associate Dean for Community Development at the University of Miami Miller School of Medicine. He is one of the Nation's leading family therapists and is an author and researcher whose primary research focus is family therapy for minority youth with drug abuse and behavioral problems. He has served on at least three other NIH Advisory Councils.

Dr. Wayne Riley is President and Chief Executive Officer of Meharry Medical College in Nashville, Tennessee. Before that, he was Vice President and Vice Dean for Health Affairs and Government Relations at Baylor College of Medicine, where his responsibilities included overseeing external affairs, multiple hospital, academic, university, and community affiliations.

Dr. Braveman is Professor of Family and Community Medicine, and Director, Center on Social Disparities in Health, University of California, San Francisco.

Dr. Hilton Hudson is Chief of Cardiothoracic Surgery at Franciscan Physicians Hospital in Munster, Indiana, and President and CEO of Hilton Publishing Company. He is Chairman of the Board of the Health Literacy Foundation.

Dr. Ruffin also announced the departure of five Council members who will rotate off the Council at the end of this meeting: Drs. Nilda Peragallo, Steven Lopez, Mario De La Rosa, Maria Soto-Greene, and Jeffrey Henderson. Dr. Ruffin also shared some sad news about a former Council member Dr. Eric Munoz, who died in March 2009. He asked for a few moments to remember him for his service to the Council, the NCMHD, and to the state of New Jersey, where he served as a legislator.

Following his remarks, Dr. Ruffin invited Council members to introduce themselves and share any updates on their work related to minority health and health disparities.

CONSIDERATION OF MINUTES

A motion to accept the minutes from the February 24, 2009 Council meeting was unanimously approved.

FUTURE MEETING DATES AND ADMINISTRATIVE MATTERS

- *Future Meetings:* September 8, 2009, and February 23, 2010.
- *Administrative Matters.* Roster changes are to be sent to Ms. Brooks.

FATH-BASED INITIATIVE CONCEPT CLEARANCE

Dr. Joyce Hunter gave some background about the development of a faith-based initiative for the NCMHD. An integral aspect of that process was a workshop convened with community leaders involved in faith-based health-related activities. She also gave an overview of how faith or religious groups are viewed and utilized in different cultures and communities, and the role that faith groups have played and can play in health-focused initiatives. Dr. Hunter described a proposed initiative for the NCMHD which would promote transdisciplinary interventions on health disparities conducted primarily with faith-based organizations or faith-motivated health programs and the research community. The Council voted unanimously to support and to continue development of the faith-based initiative concept. Many commented that the timing was right given the health care reform debates. They also outlined some points to consider as the program is developed including 1) what to call the initiative and how to market it; 2) reaching across and beyond NIH so that NCMHD does not “reinvent the wheel;” 3) the need for pilots but also sustainability of the effort; 4) making sure the issues and challenges are understood for the program to have great impact i.e. look at lessons learned; 5) evaluation is critical; and 6) how can NCMHD make this a unique model. It was agreed that these points will be taken into consideration and that some had been addressed as a part of the workshop proceedings.

NCMHD DIRECTOR’S REPORT

Dr. Ruffin presented some highlights of NCMHD activities since the last meeting.

Staff Vacancies

Dr. Ruffin stated that NCMHD is recruiting for the following positions: 1) two scientific review officers; 2) a grants management specialist; 3) a program analyst; and 4) the Scientific Director for the Intramural Research Program. Dr. Ruffin encouraged the Council members to recommend good candidates.

Programs Reports

Health Disparities Research in Minority and Underserved Populations (R01)

Dr. Ruffin announced the launch of the NCMHD investigator-initiated research program. He noted that NCMHD has been funding R01s for some time in partnership with other

Institutes and Centers (ICs). NCMHD has received 165 applications for its own program. The overall objective of the program is to support investigators whose focus will be on diseases that disproportionately affect minorities and underserved populations. First-level review will take place July 23–24, 2009. The Council will conduct second-level review at its September 2009 meeting.

ARRA

Dr. Ruffin noted that NCMHD's portion of the ARRA budget is \$52.1 million which includes a small percentage to cover administrative costs. NCMHD will use the following mechanisms and initiatives to disburse its funds:

1. Administrative Supplements:

- a. *Promoting Partnerships in Conducting Health Disparities Research with Community-Based Health Organizations and Regional/National Health Networks.* (30 applications received).
- b. *Building Capacity and Infrastructure in Health Disparity Communities* (42 applications received).

Eligible grantees from the NCMHD Centers of Excellence, Community-Based Participatory Research, and Research Infrastructure in Minority Institutions programs can apply.

2. Mini-Request for Applications (2-year limit)

- a. *Community-Based Participatory Research Program (R24):* due June 30, 2009. 185 letters of intent received.
- b. *Centers of Excellence (P20) Exploratory Centers:* due July 1, 2009
- c. *Dissertation Award Program (R36):* due June 30, 2009. This is a new initiative aimed at increasing the biomedical research workforce of individuals with an interest in health disparities research. These are individuals requiring protected time to complete their dissertation.

3. Grand Opportunities (GO) Grants: a program developed by the NIH Office of the Director (OD) to support high-impact ideas that lend themselves to short-term funding and that may lay the foundation for new fields of investigation. The program will be funded by the ICs, with potential co-funding from the NIH OD. NCMHD GO topics are:

- a. *Enhancing Information Dissemination on Health Disparities Research:* aimed at building the infrastructure for a national database on health disparities research
- b. *Trans-disciplinary Research Recovery Centers for Community Health:* to support the creation of adaptable research recovery models for communities prone to natural and man-made disasters where health disparities prevail.
- c. *Bioethics Research Infrastructure Initiative:* aimed at establishing bioethics centers to improve the recruitment and retention of minorities and other under-represented populations into clinical trials, and conduct bioethics training

- d. *Social Determinants of Health Initiative*: promotes health disparities research with a focus on social factors

Challenge Grants Program

Although NCMHD ARRA funds will not support Challenge Grants, the NCMHD participated in the NIH Office of the Director (OD) Challenge Grants Program, which addresses novel research. NCMHD identified 11 topics within 5 of the 15 broad challenge areas. NIH anticipated that 2,000 submissions would be received and 200 awards made, for a total OD expenditure of \$200 million. However, some 23,000 submissions were received, and the Institutes and Centers (IC) were asked to help pick up some of the costs.

Challenge Grants Review

NCMHD was assigned 957 Challenge Grant applications, 398 of which were primary assignments, with the balance secondary assignments. For NCMHD, funding of Challenge Grants will depend on: 1) funds received from OD; and 2) funds that may be left from the programs to which NCMHD ARRA dollars were already allocated.

POLICY AND PLANNING ACTIVITIES

Working Group on NIH Health Disparities Strategic Plan

NCMHD has established a working group to assist with the development of the next version of the NIH Health Disparities Strategic Plan. The group includes representatives from other NIH ICs, Advisory Council members, extramural scientists, and community representatives.

Dr. Ruffin reminded the Council of the importance of the strategic plan, its role, and that of the NCMHD, as well as the ICs in its development. Our goal is to carry out the congressional intent in developing the plan that will serve as our roadmap for eliminating health disparities from a research perspective. An important aspect is the opportunity for public comment.

In terms of legislative updates, the following bills were introduced into the Congress with provisions to make NCMHD an institute, and modify the eligibility criteria for the Research Endowment program:

- S-914 was introduced by Senator Arlen Specter on April 29, 2009
- H.R. 2778 was introduced by Representative Jesse Jackson Jr. on June 9, 2009.

Health Disparities Seminar Series

NCMHD will launch the monthly “NIH Health Disparities Seminar Series” at Natcher Conference Center at 2:00 p.m. on July 16, 2009. The series will regularly feature NCMHD grantees, other NIH grantees, and experts in the field of health disparities talking about their research on a thematic basis. Council member Brian D. Smedley, Ph.D. will be the inaugural speaker on the topic of “Social Determinants of Health.” The series will be open to the NIH community, other Federal agencies, and the public. Council members are invited to participate as speakers or as participants.

SCIENTIFIC PROGRAM PRESENTATIONS

“Improving Health Care Delivery: Advancing Health Equity through Comparative Effectiveness Research (CER)”--Carolyn Clancy, M.D., Director, AHRQ, HHS

Dr. Clancy gave an overview of the Agency for Healthcare Research and Quality (AHRQ), and the new Comparative Effectiveness Research (CER) landscape.

As reflected in AHRQ’s budget, Dr. Clancy explained that, patient safety and quality are AHRQ priorities, with the main focus on ambulatory care. Since 2005, AHRQ has funded CER, and it conducts a household survey that provides information about all health care.

AHRQ’s 2008 National Healthcare Disparities Report (NHDR) and the 2008 National Healthcare Quality Report (NHQR) were both well received, she reported. The two reports give AHRQ the opportunity to gauge progress over time. Every year, AHRQ sees evidence that disparities persist in health care quality and access. She noted that the magnitude and pattern of disparities are different within subpopulations; and that some disparities exist across multiple priority populations. Dr. Clancy announced that AHRQ has asked the Institute of Medicine to assess the National Healthcare Quality Report to come up with strategies for collecting data on health care quality that is standardized and could enhance their ability to collect data on race, gender and ethnicity.

Theme of the NHQR Report:

- Health care quality is suboptimal and improves at a slow pace (1.8% annually for core measures; 1.4% for all measures)
- Reporting of hospital quality is spurring improvement, but patient safety is lagging
- Health care quality measurement is evolving but much work remains

Sample findings in the NHQR Report:

- Median level of patients receiving needed care was 59% for core quality measures
- Quality improvements spread unevenly across settings of care (hospitals, home care, long-term care, ambulatory care)
- Measures of patient safety in the Quality Report indicate a 1% annual *decline*
- Need consensus on single core set of measures to be used by all payers and stakeholders to monitor improvement

Key findings in the NHDR report include:

- Sixty percent of quality measures are not improving for African American, Asian, American Indian/Alaskan Native (AI/AN), Hispanic, and poor populations (a trend for 6 years).
- Eighty percent of access measures stayed the same or worsened for Hispanics; 60 percent for African Americans and Asians; and 57 percent for poor populations.
- The proportion of new AIDS cases was 9.4 times as high for African Americans as for whites.

- The rate of new AIDS cases is more than 3 times as high for Hispanics as for non-Hispanic whites.

CER challenges include:

- Anticipating downstream effects of policy applications
- Making sure that CER is descriptive and not prescriptive
- Creating level playing fields among all stakeholders, including patients and consumers
- Using research to address concerns of patients and clinicians.

AHRQ's role in CER include:

- Providing information that can be used on the frontlines of treatment
- Helping to make decisions more consistent, transparent and rational
- Promoting an open and collaborative approach to comparative effectiveness
- Ensuring the effectiveness data is more widely used

“Overview of the Centers for Medicare and Medicaid Services Health Disparities Program” --Terris King, M.S., Deputy Director, Office of Clinical Standards and Quality, Centers for Medicare and Medicaid Services (CMS)

Mr. King gave an overview of the Office of Clinical Standards and Quality (OCSQ), which sets standards for quality in the health care system based on what science, says about clinical requirements in terms of medications, drugs, and devices. Two-and-a-half years ago, Mr. King was asked to head CMS's disparities program. At that time, the program dispersed grants to Historically Black Colleges and Universities for research into health care disparities and on interventions that might work tied to 2–3-year demonstration projects.

To expand the disparities program, the Office of Clinical Standards and Quality began by reviewing the AHRQ National Healthcare Disparities Report data and found that major disparities in diabetes for African Americans and Latinos. The OCSQ developed an initiative focused on health literacy to improve outcomes for people with diabetes. The goal now is to do baseline measurements with participating clinicians and additional measurements over three years on clinical improvement. Recruitment began in August 2008, through beneficiaries, community centers, and churches, and it has been very successful so far.

Another project in progress is a rural effort in 40 States launched about a month ago to address care transition, reducing readmission rates, as well as homelessness. A similar effort is under way in Tennessee focused on improving the health of diabetics and those suffering from other chronic illnesses. This involves over 50 physician offices.

The office launched a preventive effort in Louisiana focused on amputation rates, based on data indicating that African Americans with diabetes are three times more likely than other populations to experience lower extremity amputation.

OCSQ also started a special study with HRSA on socioeconomic factors and disparities that involves electronic health records (EHRs). The allied study is designed both to measure improvement through use of EHRs and to improve care of the poor.

The American Indian Health Research and Education Alliance (AIHREA): Healing Native Communities in the Heartland

Christine Daley, Ph.D., Research Assistant Professor, Department of Preventive Medicine and Public Health, University of Kansas (KU) Medical Center; and Mr. Thomas Edward Smith, Project Coordinator, All Nations Breath of Life Smoking Cessation Program, Johnson County Community College

Dr. Daley receives NCMHD funding through the Community Based Participatory Research program and the Loan Repayment Program. She began her presentation with a few basic facts, noting that 1) there are 563 recognized American Indian (AI) tribes in the United States, 2) AIHREA is, in part, an alliance that serves AIs, regardless of percent blood, in Kansas and the Kansas City metropolitan area, and 3) several AI students attend Haskell Indian Nations University in Lawrence, Kansas, where Dr. Daley is the Director of Community Health.

Dr. Daley is leading a Breast and Colorectal Cancer Screening Project, designed to identify what medical staff believes about needs and barriers, and what Native people believe, know, and feel with regard to these types of screening. Dr. Daley detailed major findings from breast cancer and colorectal cancer focus groups.

Major findings from breast cancer focus groups included:

- Fear of the test and the results, and fear of embarrassment
- Belief among those who had been screened that breast cancer can be prevented through diet and exercise
- Among those who had not been screened, little knowledge of risk factors, symptoms, or screening guidelines
- Belief by men under age 40 that women in their age group do not need to worry about breast cancer or be concerned about lack of insurance
- A general distrust in the Indian Health Service (IHS)
- Desire by children of breast cancer patients for their mothers to talk to them about their health and experiences.

Major findings from colorectal cancer focus groups included:

- Distrust and dislike of the test, including test preparation
- Belief among women over age 50 that this cancer is a man's disease
- Belief that Native people do not get cancer
- The possibility that IHS in Kansas City conducts colonoscopies only for diagnostic purposes
- Desire by men age 50 and older for more culturally tailored information
- Lack of health insurance and health services as a major barrier.

Analysis of data is under way, and programs are being developed to bring screening programs to the community.

Dr. Daley discussed the American Indian and Latino Community Ambassadors to Cancer Research 1-year program that is part of the NIH Partners in Research Program funded by the OD and an NCI grant. It is an opportunity for researchers to partner with community members in research. Program graduates will be asked to serve as ambassador-assistants on research teams to provide input and bring their community's needs to the attention of KU's Cancer Center.

Another project, a traveling primary care screening clinic operated in conjunction with the Heart of America Indian Center, "goes to the Center, urban health fairs, four reservations, and powwows." It provides many basic services, including HIV testing and arranging for colonoscopies, which the project subsidizes. Developmental pediatric teams also are available. Goals are to provide a culturally acceptable entrée into the health care system. Among its successes is provision of services to 1,014 individuals over a period of 9 months.

A final project described by Dr. Daley and Mr. Smith is the *All Nations Breath of Life Smoking Cessation Program*.

The original pilot included 30 participants. At 3 months, quit rates were at 65 percent; in 6 months, 25 percent. In the middle of the grant, quit rates were holding at 25 percent, with an additional 71 individuals participating. Services are provided at a variety of locations, and there are plans to run groups via telemedicine and to take the program to other States.

Teamwork in Research and Intervention to Alleviate Disparities (TRIAD-2)
Debra Wallace, Ph.D., Dauphine Doster Mastroianni Distinguished Professor, Director of the Center for the Health of Vulnerable Populations, and Associate Dean for Research, School of Nursing, University of North Carolina, Greensboro

Dr. Wallace began her remarks by noting that the University of North Carolina (UNC), Greensboro, had a R24 COE grant and now has moved to a P20 grant status. She further noted that thirty percent of UNC Greensboro's students are minorities; many first-generation college students and that fifteen percent of campus faculty are minorities.

Dr. Wallace showed a map of central North Carolina, including four Appalachian counties with double-digit unemployment rates. Winston-Salem and Greensboro are the only cities in the area. Some of the outlying counties have no health department or share one. Many hospitals contain fewer than 100 beds. In short, the project's target area is "very needy."

Dr. Wallace explained that TRIAD-2 project researchers include interdisciplinary teams from various schools, Centers, and North Carolina Central University. UNC Greensboro has a community-based campus and although it does not have a medical school, it has a school of public health. A TRIAD-2 project advantage is UNC Greensboro's preexisting linkages and trust within the community. The R24 planning grant also offered sustainable linkages to make training synergistic and to integrate the project cores.

Dr. Wallace listed her program's research core projects as follows:

- Adolescent Risk Prevention in African American Girls and Mothers (status: just completed through the P20 grant)
- Reducing Diabetes Risk Among Older African American Women
- A Tailored Nutrition Intervention for African American Child Caretakers (status: experimental group)
- Rural Latina/Latino Adolescent Health Disparities Through School of Nursing and School Counseling Services (status: year-1 research core)

TRIAD-2 has worked hard to include multidisciplinary research assistants in its training core. The four levels of research training are predoctoral trainees, master's mentees, undergraduate mentees, and Loan Repayment Program fellows. Outreach activities are a very important part of work with the community. TRIAD-2 has leveraged its resources with State money to go to other counties to examine health conditions that are not in the current studies.

When TRIAD-2 began, the faculty was all were pretenured. Since then, 10 have been tenured, two more are to be tenured, and many faculty members are now co-investigators on grants. Other notable outcomes of the Project have been:

- The project reached about 2,000 persons for health screening, changing health behavior, and increasing awareness and knowledge.
- Nine minority faculty --African Americans, Asians, and Hispanic scholars.
- The Center for the Health of Vulnerable Populations (CHVP) is up and running.
- The project engaged in development, dissemination, and translation of science; achieved community engagement with research; and built capacity for interdisciplinary and community research.
- 70% of involved students and trainees were minorities.

PUBLIC COMMENTS

There were no comments from the public.

CLOSING REMARKS

Dr. Ruffin thanked everyone for their attendance and participation in the meeting. He expressed special thanks to Council members and staff. Dr. Ruffin also reminded Council members that the Council's work will accelerate because of ARRA grant applications. Staff will be calling on members to help with expedited review of applications.

Retiring Members

Dr. Ruffin recognized the members who were rotating off the Council: Drs. Jeffrey Henderson, Stephen Lopez; Mario De La Rosa and those in absentia –Drs. Nilda Peragallo and Maria Soto-Greene.

Adjournment of Open Session

Ms. Brooks adjourned the Open Session at 4:47 p.m.

**U.S. Department of Health and Human Services (HHS)
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Tuesday, June 23, 2009

Meeting Minutes

We hereby certify that, to the best of our knowledge, the foregoing minutes are accurate and complete.

/John Ruffin/

John Ruffin, Ph.D., Chair, National Advisory Council on Minority Health and Health Disparities; Director, National Center on Minority Health and Health Disparities, NIH

/Donna A. Brooks/

Donna A. Brooks, Executive Secretary, National Center on Minority Health and Health Disparities, NIH