Report of Trans-National Institutes of Health Research Conducted in Fiscal Year 2010

Report to Congress

National Institutes of Health

Department of Health and Human Services

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Report of Trans-National Institutes of Health Research

Conducted in Fiscal Year 2010

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Table of Contents

I.	Introduction	1
II.	Overview of Collaborations Within NIH	1
III.	Scope of Report	2
IV.	Percentage of Funds Made Available in Fiscal Year 2010 by Each National Research Institute or Center for Conducting Trans-NIH Research	5
V.	Examples of Collaborative Work Between National Research Institutes and Centers	5
VI.	Conclusion	5
Appendix 1:	IC Collaborative Activity Summary – FY 2010	6
Appendix 2: I. II. III.	Examples of Collaborative Activities Not Fully Demonstrated in the Budget Data Conferences, Workshops, and Meetings Committees, Working Groups, and Task Forces Educational Campaigns and Clearinghouses	7 7 13 26
Appendix 3:	Key to Abbreviations	31

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Report to Congress

I. Introduction

Section 402A(c)(2)(B) of the Public Health Service Act (PHS Act) (42 U.S.C. 282a(c)(2)(B)), added to the PHS Act by Section 103(a) of the National Institutes of Health (NIH) Reform Act of 2006, requires that the Secretary of Health and Human Services submit an annual report to Congress identifying the percentage of funds made available by each national research institute and national center with respect to conducting or supporting research that involves collaboration between the institute or center and one or more other national research institutes or national centers (ICs). This fourth annual report provides the amount made available by each IC for conducting or supporting research that involves collaboration between that IC and one or more other ICs. This amount is expressed as the percentage of funds made available by each IC for the previous fiscal year (fiscal year 2010) for conducting or supporting trans-NIH Research. In addition, the U.S. House of Representatives Report accompanying the NIH Reform Act of 2006 recognizes that there may be collaborative work between ICs that may not be fully demonstrated in budgetary data, such as planning meetings, conferences, and day-to-day communication and information exchange between programs. Accordingly, this report provides narrative examples of inter-IC activities that fall under this category, such as collaborative conferences, workshops, Scientific Interest Groups, task forces, and educational campaigns.

II. Overview of Collaborations Within NIH

The NIH is composed of 27 ICs, each having a distinct mission. However, leaders across the NIH recognize that scientific progress often comes at the interface of traditional boundaries. Therefore, there is considerable trans-NIH collaborative activity across IC boundaries at every level of NIH operations. Trans-NIH collaborative activities can be found in all disease areas and across basic, translational, and clinical research. These collaborations can be formal or informal and can involve sharing materials, specimens, or scientific expertise. Collaborations take place at any or all stages of a research project or program, including: 1) development of a concept, initiative, or plan; 2) funding; 3) conduct of the research; 4) management and administration of the project; and 5) measurement of results. Although some collaborative activities take place day-to-day in the office and in the laboratory. This report includes the activities of 24 of the 27 ICs. For reasons discussed below, the Clinical Center, the Center for Information Technology, and the Center for Scientific Review are not part of this report.

III. Scope of Report

Inclusions:

For the purposes of this report, a trans-NIH research collaboration is defined as a formally documented, science-based effort that includes two or more ICs. Within this defined cohort, two types of extramural collaborations are included in the budget figures presented in this report: 1) grants and contracts that are cofunded by two or more ICs, and 2) grants and contracts funded in response to collaborative Funding Opportunity Announcements (FOAs) developed and announced by two or more ICs. FOAs of this type include Requests for Applications (RFAs), Requests for Proposals (RFPs), and Program Announcements (PAs). A qualifying feature of these extramural collaborative FOAs is the formal participation by multiple ICs at the outset of the activity in developing and issuing the FOA. Intramural collaborative research projects also are included within the "Total Collaborative Activities" column in the Appendix 1 table. This is the second annual report to include collaborative activities supported by the American Recovery and Reinvestment Act of 2009.

This report also provides narrative examples of formally documented collaborative activities not fully demonstrated in the budgetary data, including conferences, workshops, Scientific Interest Groups, working groups, task forces, educational campaigns, and other major labor-intensive and time-consuming activities.

Exclusions:

Informal collaborations between ICs are excluded from this report, although they occur within all programs and at all levels. Also excluded are grants funded in response to "Parent Announcements." These general announcements of guidelines for grant mechanisms (e.g., R01) do not address scientific areas and, therefore, are outside the scope of the collaborative FOAs included in this report. As the list of excluded announcements continues to be refined, some ICs may have an apparent decrease in their collaborative activities due to projects being excluded for FY 2010 that were included in the previous years' reports. As in the previous reports, grants that provide shared resources have also been excluded from this report unless they are cofunded or funded in response to collaborative program initiatives.

Also excluded from this report are collaborative activities initiated and/or led through offices within the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI). This is consistent with this report's definition of a trans-NIH collaboration and with NIH's interpretation of the legislative language. Clearly, trans-NIH collaborations are central to the missions of all DPCPSI offices, and their efforts are critical to the synergy of inter-IC collaborations of all types. The five DPCPSI offices are as follows:

• Office of Strategic Coordination (OSC), which oversees collaborative efforts across the NIH to plan, implement, and manage the programs funded via the NIH Common Fund. These programs are not included because they are the subject of a separate report, the

Common Fund Strategic Planning Report. All ICs participate in these programs, and some ICs have contributed additional funds from their own appropriations. The IC funds are represented in this report, but the dollars appropriated to the Common Fund within the Office of the Director (OD) appropriation are not.

- Office of Behavioral and Social Sciences Research (OBSSR), which (a) leads the development of priorities for increasing the scope of and support for behavioral and social science research and training at the NIH; (b) coordinates research in the behavioral and social sciences across the 27 ICs; (c) develops and facilitates new initiatives in partnership with the ICs; (d) provides leadership in disseminating findings from behavioral and social sciences research and communicating the importance of such research in the acquisition, treatment, and prevention of disease and disability; and (e) advises key NIH officials on matters relating to behavioral and social science research.
- Office of Research on Women's Health (ORWH), which (a) advises the NIH Director and staff on matters relating to research on women's health; (b) serves as the focal point for women's health research and the study of sex/gender factors at NIH; (c) promotes, stimulates, and supports efforts to improve the health of women through biomedical and behavioral research on the roles of sex and gender in health and disease; (d) ensures that women are appropriately represented in clinical studies supported by NIH; and (e) develops opportunities for the recruitment, retention, re-entry, and advancement of women in biomedical careers and advancement of careers for men and women in women's health research.
- Office of Disease Prevention (ODP), which includes the Office of Dietary Supplements, Office of Medical Applications of Research, and Office of Rare Diseases Research. ODP (a) provides overall coordination and guidance to the ICs concerning disease prevention and health promotion initiatives, policies, and activities; (b) collaborates in the formulation of research initiatives and policies that promote public health; and (c) stimulates, coordinates, and supports research on dietary supplements and on rare diseases.
- Office of AIDS Research (OAR), which has unique authorities to plan, coordinate, evaluate, and submit budget estimates for the NIH AIDS research program. OAR (a) coordinates the scientific, budgetary, legislative, and policy elements of the NIH AIDS research portfolio and sets the trans-NIH scientific priorities; (b) has established comprehensive trans-NIH planning, budgeting, and portfolio analysis processes to identify the highest priority areas of scientific opportunity, enhance collaboration, minimize duplication, and ensure that precious research dollars are invested effectively and efficiently; (c) prepares a Presidential by-pass budget; (d) identifies emerging scientific opportunities and public health challenges that require focused attention, and manages and facilitates multi-Institute and trans-Institute activities to address those needs; (e) fosters research by designating funds and supplements to jump-start or pilot program areas; (f) sponsors reviews or evaluations of research program areas; (g) supports a number of initiatives to enhance dissemination of research findings to

researchers, physicians, institutions, communities, constituency groups, and patients; and (h) facilitates international AIDS research and training.

The budget numbers exclude collaborative efforts coordinated through the NIH Clinical Center because the Clinical Center budget is funded through a mandatory contribution from the ICs as a standard percentage of the intramural IC budgets. However, it is important to note that the Clinical Center coordinates a range of trans-NIH activities, including the highly successful Bench-to-Bedside awards program. This program is supported through a number of OD offices, in addition to voluntary contributions from 17 ICs. The Bench-to-Bedside awards program was created to speed translation of promising laboratory discoveries into new medical treatments by encouraging collaborations among basic scientists and clinical investigators. Since the Bench-to-Bedside program began over 12 years ago, 176 collaborative projects have received funding, representing partnerships among multiple ICs.

Other trans-NIH activities are coordinated through centers of excellence established within the Clinical Center to better integrate a number of scientific areas within the NIH community. The Center for Neuroscience and Regenerative Medicine focuses on the discovery of methods to better intervene and prevent the long-term consequences resulting from traumatic brain injury. The Clinical Center's new Center for Interventional Oncology focuses on localized treatment and drug delivery by use of advanced imaging technologies, including cutting-edge magnetic resonance imaging, positron emission tomography, and computed tomography, combined with the capability to use all three technologies simultaneously to navigate a therapeutic device through the body. The Center for Infectious Disease Imaging is a collaborative program that seeks to use advanced anatomic, functional, and molecular imaging methods to identify and assess the manifestations and progression of infectious disease. The Imaging Sciences Training Program provides trainees with a background in state-of-the-art methodology in imaging technology while working collaboratively in a variety of research disciplines between the Clinical Center and various ICs.

Also excluded from this report are: (a) collaborative efforts coordinated through the Center for Information Technology, whose mission is to provide, coordinate, and manage information technology, and to advance computational science; (b) the Center for Scientific Review, which focuses on peer review of grant applications; (c) activities involving NIH collaboration with other agencies within HHS (these types of activities are included in the FY 2009 Intra-HHS Collaborations Report); (d) collaborations between individual ICs and private-sector partners; and (e) collaborations that are not supported through the ICs' budgets. The latter category includes a number of major NIH efforts, such as the National Children's Study, the Special Statutory Funding Program for Type 1 Diabetes Research, and the Superfund program. These are collaborative efforts by design, jointly planned and managed by multiple ICs. However, as with activities supported through the Common Fund, the fact that they are not supported through the IC budgets their inclusion in the totals and percentages that are presented in Appendix 1.

IV. Percentage of Funds Made Available in Fiscal Year 2010 by Each National Research Institute or Center for Conducting Trans-NIH Research

Appendix 1 presents the percentage of funds made available by each research IC for the previous fiscal year (FY 2010) for conducting trans-NIH research. The figures presented in this table represent the sum of collaborative activities in three areas: extramural grants, extramural contracts, and intramural research projects. Section III of this report describes the categories of extramural grants and contracts that are included.

Intramural collaborations are identified through the NIH Intramural Database. As with extramural projects, reporting on intramural projects is limited to formal collaborations between two or more ICs. In each case, the total FY 2010 budget for a collaborative intramural research project is credited wholly to the lead IC because through this database it is not possible to apportion the effort or budget across multiple ICs. It is important to note that three of the ICs listed in Appendix 1 do not have intramural research programs.

As stated in Section III, this is the second annual report to include collaborative activities supported by the American Recovery and Reinvestment Act of 2009 (ARRA). Collaborative research supported by ARRA contributed \$1,268,722,609.00 to the IC grand total shown in Appendix 1.

V. Examples of Collaborative Work Between National Research Institutes and Centers

Appendix 2 highlights selected examples of collaborative activities across ICs that are not fully demonstrated in budgetary data. The activities are grouped within the following categories: (a) conferences, workshops, and meetings; (b) committees, working groups, and task forces; and (c) educational campaigns and clearinghouses. The list is intended to illustrate the range of collaborative activities, both extramural and intramural, that occur across the ICs. The list is not meant to be comprehensive; rather, it is meant to provide a few representative activities within each category. A complete list would be extremely long, since the NIH Intramural Scientific Interest Groups alone number over 100.

VI. Conclusion

NIH has a strong commitment to collaborative research, as evidenced by joint efforts at all levels. Although many inter-IC collaborative activities are typically not as visible as NIH Common Fund programs and other high-profile trans-NIH collaborations, Appendix 1 illustrates that a significant percentage of the ICs' budgets support these important activities. It also is clear that the focus and breadth of an IC's mission affects the percentage of funds made available by an IC for conducting or supporting trans-NIH research. NIH appreciates the opportunity to offer specific examples of ongoing joint activities.

Appendix 1: IC Collaborative Activity Summary – FY 2010

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Funding IC	Total IC Actual Obligations (Non- ARRA and ARRA Appropriations)	Total Collaborative Activities	Percent for Collaborative Activities
FIC	\$ 77,109	\$ 57,713	74.8%
NCCAM	142,526	53,734	37.7%
NCI	5,534,968	898,246	16.2%
NCRR	1,337,032	623,554	46.6%
NEI	773,051	104,937	13.6%
NHGRI	559,353	152,269	27.2%
NHLBI	3,419,645	563,013	16.5%
NIA	1,224,578	198,196	16.2%
NIAAA	507,448	102,079	20.1%
NIAID	5,006,047	735,861	14.7%
NIAMS	588,235	118,391	20.1%
NIBIB	345,893	124,109	35.9%
NICHD	1,477,582	391,212	26.5%
NIDA	1,185,249	265,212	22.4%
NIDCD	442,000	57,925	13.1%
NIDCR	453,084	98,911	21.8%
NIDDK	2,034,580	298,100	14.7%
NIEHS	756,228	130,883	17.3%
NIGMS	2,204,165	282,553	12.8%
NIMH	1,638,576	479,045	29.2%
NIMHD	231,073	46,997	20.3%
NINDS	1,791,628	376,168	21.0%
NINR	163,118	51,722	31.7%
NLM	386,605	36,874	<u>9.5%</u>
NIH	32,279,773	6,247,704	19.4%

Appendix 2: Examples of Collaborative Activities Not Fully Demonstrated in the Budget Data

I. Conferences, Workshops, and Meetings

1. 12th International Conference on Malignancies in AIDS and Other Acquired Immunodeficiencies (ICMAOI2010)

This biannual Conference provided a forum to present and discuss basic, epidemiologic, and clinical aspects of research on malignancies in HIV-infected and other immunosuppressed individuals. The ICMAOI was designed to facilitate the exchange of information between laboratory and clinical investigators to accelerate the translation of basic scientific discoveries into clinical applications. The ICMAOI agenda focused on advances in clinical investigation of malignant diseases associated with HIV and other acquired immunodeficiency states, including developments in viral oncology, immunology, genetics, epidemiology, pathogenesis, drug discovery, and early diagnosis. The conference was held April 26-27, 2010.

Participating Institutes and Centers: NCI and NIDCR

Web site: http://www.capconcorp.com/meeting/12thICMAOI/cmeactivity.asp

2. 2010 Quantitative and Systems Pharmacology Workshop

This September 9-10, 2010, workshop brought together researchers in pharmacology, pharmacokinetics, pharmacodynamics, systems biology, computer modeling, and related areas to discuss how systems biology is contributing to drug discovery and understanding drug actions now and in the future.

Participating Institutes and Centers: NIGMS, CC, NCI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDA, NINR, NLM, and FDA

Web site: http://meetings.nigms.nih.gov/index.cfm?event=home&ID=8316

3. Advanced Training Institute for Health Behavior Theory

NIDCR partnered with multiple NIH Institutes and Centers to plan and implement an intensive, advanced training in health behavior theory held in July 2010. Trainee-participants were selected via a competitive application process, which yielded a cohort of 35 participants from a variety of disciplines, and with expertise in a variety of health behaviors. Core faculty mentored participants throughout the seven-day training during group exercises and individual consultations, and visiting faculty lectured on essential topics in health behavior theory. The training aimed to equip promising investigators with tools to conduct rigorous, cutting-edge, theory-based health research.

Participating Institutes and Centers: NCI, NHLBI, NIAAA, NIAID, NIDA, NIDCR, and OBSSR

4. Asthma Outcomes Workshop

This workshop, held March 15-16, 2010, focused on determining validated outcome measures to include in NIH-sponsored asthma clinical trials and large observational study initiatives to ensure valid comparisons across studies. The workshop included over 80 participants from Federal agencies, the scientific community, pharmaceutical companies, and volunteer organizations.

Participating Institutes and Centers: NHLBI, NIA, NIAID, NICHD, NIEHS, NIMHD, and NINR

5. Cardiovascular Disease Prevention in Rural Areas

This June 14-15, 2010, workshop addressed interventions that will enhance communitybased participatory approaches to cardiovascular disease (CVD) prevention in high-risk rural areas.

Participating Institutes and Centers: NHLBI, NIMHD, NCI, and OBSSR

6. Executive Function in Preschool Children: Current Knowledge and Research Opportunities

On June 8-9, 2010, a workshop was held to review the current state of the research on executive function (EF) competence in preschoolers to consider how best to define the construct and to propose promising areas of research ripe for advancement and translation. This workshop focused on novel interventions to improve EF skills in young children from risk groups or disadvantaged backgrounds and to build an agenda for future basic and translational research in EF development in the preschool period.

Participating Institutes and Centers: NIDA, NICHD, and OBSSR

Web site: http://www.nichd.nih.gov/about/meetings/2010/060810.cfm

7. Expert Panel Discussion on Pharmacological Management of Chronic Pain in Older Adults

The goals of this meeting were to (1) receive expert recommendations on research priorities for improving pharmacological management of chronic pain in older adults with particular emphasis on appropriate uses of opioids and nonsteroidal anti-inflammatory drugs (NSAIDs); (2) summarize major knowledge gaps on high-impact issues related to pharmacological management of chronic pain in older adults; and (3) develop a set of recommended research strategies to be pursued to address the research knowledge gaps and research needs in this special population. This Expert Panel meeting was held on September 14-15, 2010.

<u>Participating Institutes and Centers</u>: NIA, CC, FIC, NCCAM, NCRR, NEI, NIAAA, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIGMS, NIMH, NINDS, NINR, OBSSR, ORDR, ORWH, and OTT

8. Exploring Interconnections: A Network Dynamics Workshop for Understanding and Preventing Adolescent and Young Adult Substance Abuse

This meeting, held on January 13-14, 2010, brought together network researchers and a select group of drug abuse epidemiologists, prevention, and services researchers to share findings from social network research. Participants also discussed obstacles and opportunities for stimulating scientific advancements and translating these findings to understand, prevent, and deliver treatment services/recovery support for adolescent and young adult substance abuse.

Participating Institutes and Centers: NIDA, NIA, NIAAA, NICHD, and OBSSR

Web site: http://www.seiservices.com/nida/1014059/index.asp

9. Inter-Institute Workshop on Optical Diagnostic and Biophotonic Methods from Bench to Bedside

This October 1-2, 2009, workshop brought together experts in the diagnosis and treatment of several important health issues. The format included talks by leading experts in the biophotonics field, as well as expert panels that addressed the need for developing fast cures and overcoming barriers to translational medicine. In addition to presentations by invited speakers, the event featured two poster sessions. The workshop presented efforts at the forefront of discovery and development of the latest light-based tools for applications to diagnose and treat disease and apply technologies to address cures in specific organ systems and areas including the eye, brain, and breast; the vascular system; molecular probes and targets; and microscopes.

Participating Institutes and Centers: NICHD, CSR, NCI, NEI, NHLBI, NIBIB, and NINDS

Web site: http://spie.org/NIH-Workshop.xml

10. mHealth Mobile Health Summit

The two-day event held on October 29-30, 2009, explored the role of biomedical research as the driver for the development of compelling applications based on mobile technology. The Summit brought together U.S. and international researchers to assess current policies regarding mobile health technologies and their use in reducing or eliminating domestic and global health disparities; build bridges between the scientific community and mobile technology developers to identify mHealth solutions; highlight scientific opportunities and challenges in using mobile technologies to improve public health; and discuss and craft a vision for the development and use of mobile technologies in the future.

Participating Institutes and Centers: FIC, NCI, NHLBI, NIA, NIAID, NIMH, NIMHD, NLM, and OBSSR

11. Next-Generation Analytic Tools for Large-Scale Genetic Epidemiology Studies of Complex Diseases

This workshop, held September 15-16, 2010, in Bethesda, Maryland, was developed by a trans-NIH group and is supported by NCI. The goal is to facilitate discussions on 1) statistical strategies/methods to efficiently identify genetic and environmental factors contributing to complex disease risk; and 2) evaluating, developing, and applying these strategies for the design, analysis and interpretation of large-scale complex disease association studies. Sessions focused on study design, optimal statistical methods, and methods for integrating other data sources for studying [gene x gene] and [gene x environment] interaction, complex phenotypes, and rare variants and next generation sequencing. Another set of sessions focused on the analytic challenges associated with simulation modeling and on computational resources and data management.

Participating Institutes and Centers: NCI, NHGRI, NHLBI, NIDCR, and NIEHS

Web site: http://www.blsmeetings.net/nextgenerationanalytictools/

12. NIMH Workshop on Opportunities and Programs for Rural Health

This workshop was held on June 2, 2010, at the National Association for Rural Mental Health (NARMH) annual meeting. Researchers, health care providers, family members, advocates, and policymakers attended the meeting to learn about effective programs and practices and new discoveries. Participants also communicated about rural behavioral health policy, rural mental health research, and reducing health disparities for rural populations.

Participating Institutes and Centers: NIMH, NIA, NIDA, NINR, AHRQ, HRSA, SAMHSA, and USDA

Web site: http://www.narmh.org/conferences/2010/agenda.aspx

13. NIMHD Translational Health Disparities Course

The NIMHD translational health disparities course, held September 20 through October 1, 2010, provided two weeks of specialized instruction in the principles of health disparities research, with a focus on the concepts, methods, and applications for translation. The course focused on integration of disciplines (including biological, social, behavioral, physical, and environmental sciences, and law and economics) to understand science, practice, and policy issues in health disparities research.

Participating Institutes and Centers: NIMHD, NCI, NIAMS, NINDS, and OBSSR

Web site: http://ncmhd.nih.gov/course%20syllabus03.pdf

14. Nonverbal School-Aged Children with Autism: Research Needs and Opportunities

This multidisciplinary workshop, held April 13-14, 2010, addressed the state of the empirical knowledge about, and research opportunities regarding, the substantial subgroup of children with autism spectrum disorders who have not developed functional verbal language by five years of age.

Participating Institutes and Centers: NIDCD, NIMH, and NICHD

Web site: http://www.nidcd.nih.gov/funding/programs/10autism/

15. Personal Motion Technologies for Healthy Independent Living

This June 2010 workshop brought together 60 clinicians, academic researchers, engineers, patient advocates, caregivers, members of the public, NIH staff, and representatives from other Federal agencies (CMS, FDA, NSF, and VA) to discuss technologies that could enable older adults to live independently longer. The ability of older persons to remain physically active inside and outside of their homes and thereby maintain independent living is an important public health goal. However, at present, there are no good ways to continuously monitor and identify problems, other than personal or caregiver reports. The development of improved non- or minimally-invasive technologies that would allow serial functional measurements for an individual in the home or on-the-go over an extended period of time would be of significant benefit to individuals and public health.

Participating Institutes and Centers: NIBIB, NIA, NICHD, NINDS, and OBSSR

Web site: http://www.nibib.nih.gov/NewsEvents/SympReports/2010June22

16. Rejuvenation of the Aged Immune System Workshop

In September 2010, NIAID and NIA investigators presented their research progress on the rejuvenation of the aged immune system. Researchers examined the immunological consequences of methods to prevent or reverse the progressive shrinking of the thymus over time—thymic involution—and the decline of naïve T cell production, differentiation, and function in the aged population.

Participating Institutes and Centers: NIAID and NIA

17. Synthetic Biology Workshop

Synthetic biology is an emerging field of research at the intersection of engineering and biology. The workshop, held on April 12-13, 2010, in Bethesda, Maryland, was designed to bring together a diverse group of scientists to discuss the future of synthetic biology in biomedicine, and included five specific aims: (1) communicate progress in the emerging field of synthetic biology; (2) identify potential applications of synthetic biology in cancer research; (3) discuss bioethical implications and risk management; (4) discuss opportunities for fundamental impact in biomedicine; and, (5) identify challenges and

needs for future development. Invited speakers included leading experts in synthetic biology and cancer biology with diverse backgrounds in biology, engineering, physics, mathematics, computer science, and chemistry.

Participating Institutes and Centers: NCI and NIGMS

18. Systemic Lupus Erythematosus: From Mouse Models to Human Disease and Treatment

This September 2-3, 2010, meeting brought together basic research scientists working on models of autoimmune disease relevant to lupus with clinicians treating lupus patients. The purpose of this meeting was to have participants come with open minds and discuss the clinical and molecular similarities, as well as differences, seen in human disease and animal models. In addition, input was sought from attendees regarding what clinical markers would be most important for monitoring the disease and assessing the effectiveness of treatment in humans and mouse models.

Participating Institutes and Centers: NIAMS, NIAID, NCI, and ORWH

19. Workshop on Control/Comparison Groups for Trials of Non-Pharmacologic Interventions

The purpose of this April 26-27, 2010, workshop was to review the strengths and weaknesses of the various control/comparison groups used in studies of non-pharmacological interventions (NPI) and the most appropriate use of these control/comparison groups. The workshop addressed the following topics: Does the intervention work? What are the major effective mechanism(s) of the NPI? Is the NPI as good as (or better than) another intervention? And does the NPI improve standard-of-care?

Participating Institutes and Centers: NCCAM, NCI, NHLBI, NIA, NIAAA, NIAMS, NIMH, NINDS, NINR, and OBSSR

Web site: http://nccam.nih.gov/news/events/control_group.htm

20. Workshop on Pain Measurement Scales: Current Issues and Future Directions

The objectives of this workshop were to (1) review the utility, limits, and potential improvement of commonly used pain scales; (2) address the use and validation of biomarkers in the assessment of pain traits; and (3) discuss the impact of patient characteristics on individual variation in pain perception. This workshop, held on January 27, 2010, laid the groundwork for future research on pain and analgesic treatments in a variety of populations.

<u>Participating Institutes and Centers</u>: NIDA, CC, FIC, NCCAM, NCRR, NEI, NIA, NIAAA, NIAMS, NIBIB, NICHD, NIDCD, NIDCR, NIDDK, NIGMS, NIMH, NINDS, NINR, OBSSR, ORDR, ORWH, and OTT

Web site: http://www.seiservices.com/nida/1014064/index.asp

21. Workshop on Virtual Reality Technologies for Research and Education in Obesity and Diabetes

This workshop, held July 15-16, 2010, explored the research potential of virtual reality (VR) technologies as tools for behavioral and neuroscience studies in diabetes and obesity and the practical potential of VR technologies for fostering more effective use of diabetes- and obesity-related nutrition and lifestyle information.

Participating Institutes and Centers: NHLBI, NCI, NICHD, NIDDK, OBSSR, ORWH, and DOD

Web site: http://www.nhlbi.nih.gov/meetings/VRT/index.htm

II. Committees, Working Groups, and Task Forces

1. Asthma Phenotypes Task Force

This task force develops definitions for specific asthma phenotypes and promotes a phenotype checklist for use in describing research study populations.

Participating Institutes and Centers: NHLBI, NIAID, and NIMHD

2. Bioengineering Research Partnerships Committee

This committee focuses on basic, applied, and translational multidisciplinary research that addresses important biological, clinical, or biomedical research problems. An initiative soliciting research applications has been published.

Participating Institutes and Centers: NIBIB, NCI, NEI, NHLBI, NIA, NIAAA, NICHD, NIDA, NIDCR, NIDCD, NIEHS, and NINDS

3. Four Institute Gene Therapy Program

This program provides an interactive and synergistic environment in which scientists and trainees from four different Institutes, and many different disciplines, work together toward the common goal of developing new therapeutic modalities for human disease. The essential goal of this program is to create a new cooperative and interactive program between Institutes to develop clinical gene therapy protocols with maximum efficiency and minimum duplication of efforts and resources. The program has been cited as a meritorious model for collaborative interactions between Institutes for clinical research in the 21st century.

Participating Institutes and Centers: NIDCR, NEI, NHGRI, and NIDCD

4. Health Literacy Work Group

This work group encourages empirical research through trans-NIH funding announcements on health literacy concepts, theory, and interventions as these relate to the HHS' public health priorities that are outlined in its HealthierUS and Healthy People 2010 initiatives. Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

<u>Participating Institutes and Centers</u>: NCI, NHLBI, NIA, NIBIB, NIDCD, NIDCR, NIEHS, NIMH, NIMHD, NINR, NLM, and OBSSR

5. IC Animal Events Response Committee

This committee provides a mechanism to inform Institutes and Centers of efforts to promote best practices in research with animals.

Participating Institutes and Centers: All NIH Institutes and Centers

6. Knowledge Management and Health: Translational Applications for Semantic Abstraction Technologies

The purpose of this collaboration is to develop advanced information management applications to support the development of clinical practice guidelines. The underlying methodology is to extend and adapt Semantic MEDLINE, a biomedical information management system under development at the Lister Hill National Center for Biomedical Communications, NLM.

Participating Institutes and Centers: NLM and NHLBI

7. Muscular Dystrophy Coordinating Committee

This committee coordinates activities relevant to the various forms of muscular dystrophy across NIH and other Federal agencies. The committee also includes members from patient organizations. Strategic planning efforts by the Coordinating Committee led to the development of an Action Plan for the Muscular Dystrophies (approved in December 2005), which contains specific research objectives appropriate to the missions of all committee member agencies and organizations and thus serves as a central focus for coordination of research.

Participating Institutes and Centers: NINDS, NHLBI, NIAMS, and NICHD

Web site: http://www.ninds.nih.gov/find_people/groups/mdcc/index.htm

8. NanoRegenerative Medicine Working Group

This working group develops new initiatives that support nanotechnology-based projects to improve understanding of the unique properties of clinically relevant nanomaterials for

regeneration. It facilitates communication among other NIH task forces that have an interest in this emerging area of science.

Participating Institutes and Centers: NIBIB, NCI, NHLBI, NIDCR, and NIST

9. NIH Autism Coordinating Committee

In 1997, at the request of Congress, NIH formed the Autism Coordinating Committee (NIH/ACC) to enhance the quality, pace, and coordination of efforts at NIH to find a cure for autism. Since then, the NIH/ACC has been instrumental in the research into, understanding of, and advances in autism (e.g., the creation of several research centers and networks to enhance the coordination and focus of autism researchers throughout the country).

Participating Institutes and Centers: NIMH, NCCAM, NIAID, NICHD, NIDCD, NIEHS, NINDS, and NINR

Web site: http://www.nimh.nih.gov/research-funding/scientific-meetings/recurringmeetings/iacc/nih-initiatives/nih-autism-coordinating-committee.shtml

10. NIH Biomedical Information Science and Technology Initiative Consortium (**BISTIC**)

The mission of this consortium is to make optimal use of computer science and technology to address problems in biology and medicine by fostering new basic understandings, collaborations, and trans-disciplinary initiatives between the computational and biomedical sciences.

<u>Participating Institutes and Centers</u>: NIGMS, CC, CIT, CSR, DPCPSI, FIC, NCI, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIEHS, NIMH, NIMHD, NINDS, NINR, NLM, ODP, OER, OIR, OLPA, OM, ORS, and OSP

Web site: http://www.bisti.nih.gov/

11. NIH Cognitive and Emotional Health Project Steering Committee

The Cognitive and Emotional Health Project (CEHP) is an ongoing trans-NIH initiative to assess the state of epidemiologic research on demographic, social, and biologic determinants of cognitive and emotional health in aging populations and the pathways by which cognitive and emotional health may reciprocally influence each other.

Participating Institutes and Centers: NIMH, NIA, and NINDS

Web site: http://trans.nih.gov/CEHP/

12. NIH End-of-Life/Palliative Care Scientific Interest Group

This interest group serves as an important source for ideas and discussions of ongoing activities in end-of-life and palliative care and provides a forum to foster career development, investigator training, and opportunities to collaborate on new initiatives.

Participating Institutes and Centers: NCI, CC, NCCAM, NHLBI, NIA, and NINR

Web site: http://sigs.nih.gov/eolpc/Pages/default.aspx

13. NIH Financial Conflict of Interest Committee

The purpose of this work group is to develop Financial Conflict of Interest (FCOI) regulations pertaining to grants, cooperative agreements, and contracts. A new proposed FCOI regulation was published as a Notice of Proposed Rulemaking for public comment. The final step in the process is the posting of a Final Rule. A second charge to the committee is to assist Institute and Center extramural officials in evaluating complex FCOI issues, especially those involved with clinical trial networks. This standing committee meets on an as-needed basis. Panel members are expected to review and analyze file materials in advance of the meetings and participate in discussions the purpose of which is to provide guidance and advice on managing FCOIs.

Participating Institutes and Centers: NIDA, NCCAM, NCI, NEI, NHLBI, NIA, NICHD, NIDCR, NIDDK, NIGMS, NIMH, NLM, and OD

14. NIH Health Disparities Seminar Series

NIMHD sponsors the monthly NIH Health Disparities Seminar Series. The forum disseminates information on advances, gaps, and current issues related to health disparities research. It features national and international health disparities research experts, including many funded by NIMHD, other NIH Institutes and Centers, and Federal agency partners. Each seminar focuses on a specific theme.

Participating Institutes and Centers: All NIH Institutes and Centers

15. NIH International Tuberculosis Working Group

NIH tuberculosis (TB) research is coordinated through monthly meetings of the NIH International TB Working Group. NIH-funded domestic and international research includes studies to characterize drug resistance; the identification, preclinical development, and clinical evaluation of new drugs, diagnostics, and vaccines; and studies of the epidemiology and transmission of TB, including research addressing HIV/TB coinfection and TB in high-risk populations. Those meetings often are attended by experts from other agencies as well, including USAID, FDA, and CDC.

Participating Institutes and Centers: NIAID, FIC, NHLBI, NICHD, NIDA, and NIGMS

16. NIH Molecular Genetics Testing Subcommittee

The NIH Molecular Genetics Testing Subcommittee of the NIH Medical Executive Committee was convened in January 2008 to evaluate the recent history of molecular genetic testing and payment strategies at the NIH Clinical Center. A long-term goal is a trans-NIH molecular genetics testing facility to meet the needs of the Clinical Center patient population, contribute to the NIH training and education mission, and serve as a nidus for innovative intramural-extramural research partnerships. The Subcommittee will continue to function to assist the Clinical Center in negotiating test prices with external commercial laboratories, to ensure optimal test ordering by users of the Clinical Center, and to advise Clinical Center leadership on the evolving role of molecular genetic testing in clinical medicine and translational research.

Participating Institutes and Centers: NICHD, CC, NCI, NEI, NHGRI, NIAMS, and NINDS

17. NIH Neuroprosthesis Group

The Neuroprosthesis Group (NPG) is a working group of program officers across NIH with an interest in promoting neuroprosthesis and neuroengineering research. Activities include the discussion of planning trans-NIH initiatives, cofunding grants and contracts, and participating on joint site visits to mutually funded investigators.

Participating Institutes and Centers: NIBIB, NICHD, NIDCD, NIMH, and NINDS

18. NIH Obesity Research Task Force

Given the importance of the obesity epidemic as a public health problem, the NIH Obesity Research Task Force was established to accelerate progress in obesity research across NIH. The task force has been instrumental in fostering trans-NIH collaboration in obesity research, including basic, clinical, and population studies. The task force also sponsors an NIH seminar series on obesity research topics.

<u>Participating Institutes and Centers</u>: NIDDK, NHLBI, NICHD, NCI, CSR, DNRC, FIC, NCCAM, NCRR, NEI, NHGRI, NIA, NIAAA, NIAMS, NIBIB, NIDA, NIDCR, NIEHS, NIMH, NIMHD, NINDS, NINR, OBSSR, ODP, ODS, ORWH, and OSP

Web site: http://obesityresearch.nih.gov

19. NIH Pain Consortium

The NIH Pain Consortium was established to enhance pain research and promote collaboration among researchers across the many NIH Institutes and Centers that have programs and activities addressing pain. These activities include research on sensory and basic mechanisms, as well as the emotional and biobehavioral aspects of pain. Age, sex, hormones, gender, ethnicity, and genetics all play a role in pain response and perception. The hope is that through increased knowledge of basic pain mechanisms, better pain management will result.

<u>Participating Institutes and Centers</u>: NIDA, CC, FIC, NCCAM, NCI, NCRR, NEI, NIA, NIAAA, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIGMS, NIMH, NINDS, NINR, OBSSR, ORDR, ORWH, and OTT

Web site: http://painconsortium.nih.gov

20. NIH Proteomics Interest Group

The Proteomics Interest Group (ProtIG) is an NIH Special Interest Group that organizes seminars and workshops in relevant areas of proteomics, including talks on separation and protein identification methods, determination of post-translational modifications, protein-protein interactions, and bioinformatics and data management. A monthly seminar series is held to foster interaction among the Institutes and Centers and the research community.

Participating Institutes and Centers: NHLBI, NCI, NCRR, NHGRI, NIAAA, NIAID, NIAMS, NICHD, NIDDK, NIEHS, NIMH, NINDS, and NLM

Web site: http://proteome.nih.gov

21. NIH Scientific Directors' Subcommittee on Biorepository Practices and Guidelines

The NIH Scientific Directors' Subcommittee on Biorepository Practices and Guidelines within the Intramural Research Program (IRP) was formed to make recommendations to the Scientific Directors concerning biorepository practices and policies within IRP. The Subcommittee was charged with: (a) determining the scope and current conditions of biospecimen storage across the IRP; (b) identifying steps needed to meet "best practices" guidelines for biospecimen storage; (c) evaluating use of local harmonized biorepositories versus creation of a centralized facility; (d) evaluating inventory tracking systems that can be used to manage biospecimen collections and meet reporting requirements; and (e) considering implementation for new specimen collections versus legacy collections.

Participating Institutes and Centers: NCI, CC, NHGRI, NHLBI, NIAID, NICHD, NIDCD, NIDDK, NIEHS, NIMH, and NINR

22. NIH Sequencing Data Sharing Policy Working Group

This working group will describe the technical issues that need to be taken into account in the development of an NIH-wide policy for the deposition and release of data from sequencing projects, specifically including those using "next-generation" sequencing instruments.

Participating Institutes and Centers: NHGRI, NCI, NHLBI, NIA, NIAID, NIDA, NIDDK, NIMH, NINDS, and NLM

23. NIH Stem Cell Task Force

The purpose of the task force is to enable and accelerate the pace of stem cell research by identifying rate limiting resources and developing initiatives to overcome barriers to progress.

<u>Participating Institutes and Centers</u>: NINDS, NCI, NCRR, NEI, NHLBI, NIAAA, NICHD, NIDCD, NIDCR, NIDDK, NIGMS, NIMH, OER, OSP, and OTT

Web site: http://stemcells.nih.gov/policy/taskforce/

24. NIH Task Force on the Inclusion of Women and Minorities in Clinical Trials

This task force was formed to consider the strengths and weaknesses in accomplishing the goals of the NIH policy for including women and minorities in NIH-funded clinical research.

<u>Participating Institutes and Centers:</u> FIC, NCI, NHLBI, NIAID, NIAMS, NIBIB, NICHD NIMH, NIMHD, DPCPSI, OAR, OER, OIR, ORWH, and OSP

25. NIH Working Group on Down Syndrome

This trans-NIH working group developed, with outside scientific and public input, the 2007 NIH Research Plan on Down Syndrome. The group is now charged with implementing that plan through the coordination of ongoing and new NIH-supported research efforts targeted to the areas of greatest scientific opportunity, especially the development of future treatments and the creation of the research resources (registry, database, biobank) necessary to move the field forward.

<u>Participating Institutes and Centers:</u> NICHD, NCI, NHLBI, NIA, NIMH, NINDS, NINR, and OD/NIH Library.

26. Participant Protection and Data Management Steering Committee

This committee advises the Senior Oversight Committee of the programmatic and policy needs and opportunities related to implementation of NIH's data sharing policy for genome-wide association studies. The committee has focused on developing common processes and forms for NIH's Data Access Committees and provided a forum for discussing implementation issues.

<u>Participating Institutes and Centers</u>: All NIH Institutes and Centers with a Data Access Committee (currently NCI, NHGRI, NHLBI, NIAID, NICHD, NIDA, NIDCR, NIDDK, NIGMS, NIMH, NINDS, NLM, and OD)

Web site: http://grants.nih.gov/grants/gwas/

27. PhenX Project – Genome-Wide Association Studies

PhenX is a three-year project led by RTI International and coordinated by NHGRI to contribute to the integration of genetics and epidemiologic research. The project has prioritized 20 research domains related to complex diseases and environmental exposures. Consensus building is being used to develop a recommended minimal set of high priority measures for use in genome-wide association studies and other large-scale genomic research efforts. High priority measures will maximize benefits of future research by enabling cross-study comparisons and analysis. Selection and specification of the measures are driven by the scientific community via the PhenX Steering Committee, Working Groups, and PhenX Surveys.

Participating Institutes and Centers: All NIH Institutes and Centers

28. Public Private Partnerships

This trans-NIH committee fosters and coordinates public-private partnerships for the benefit of research.

Participating Institutes and Centers: All NIH Institutes and Centers

29. Quantitative Systems Pharmacology Working Group

This working group meets periodically and has organized two workshops on systems pharmacology as an emerging field. Systems pharmacology explicitly seeks to incorporate classical approaches from physiology, pharmacology, and cell biology and is not limited to "omics" and bioinformatics analysis. Success in quantitative and systems pharmacology approaches will make it possible to discover and design better drugs, predict patient-specific responses to therapy, and ultimately improve clinical outcomes.

Participating Institutes and Centers: NIGMS, NCI, and NIBIB

30. Self Care Working Group

This working group was formed to identify shared interests across Institutes, Centers, and Offices related to the self care choices individuals make to promote their health and well being. The group is working to create initiatives in this shared area of interest.

Participating Institutes and Centers: NCCAM, NHLBI, NICHD, NINR, and OBSSR

31. Special Populations Research Forum

This forum provides a trans-NIH platform for sharing and examining programs and initiatives designed to enhance and accelerate the development of research careers of individuals from underrepresented (racial/ethnic and health disparity) populations. The forum ultimately seeks to consider a broad range of activities pertinent to the conceptualization, implementation, review, administration, management, and evaluation

of research, training, and outreach of programs based in institutions serving underrepresented populations.

Participating Institutes and Centers: All NIH Institutes and Centers

32. Systems Biology Scientific Interest Group

The Systems Biology Scientific Interest Group (SysBioSIG) sponsors activities exploring the diverse aspects of systems biology. SysBioSIG hosts seminars and workshops to exchange ideas between scientists conducting research in systems biology.

<u>Participating Institutes and Centers</u>: NHLBI, NCI, NCRR, NHGRI, NIAAA, NIAID, NIAMS, NICHD, NIDDK, NIEHS, NIMH, NINDS, and NLM

33. Translational Research Interest Group

The purpose of this group is to bring physicians and scientists from various disciplines together to discuss (1) efficient ways to accelerate the application of biomedical research discoveries to better help patients, and (2) the translation of clinical research observations into the development of improved preclinical disease models. This intramural scientific interest group coordinates seminars and workshops to help bridge the gap between laboratory research and clinical applications.

<u>Participating Institutes and Centers</u>: NIAID, CC, CSR, NCI, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NIBIB, NICHD, NIDA, NIDCR, NIDDK, NIEHS, NIGMS, NIMH, NINDS, NINR, NLM, and FDA

Web site: http://sigs.nih.gov/trig/Pages/default.aspx

34. Trans-NIH Angiogenesis Program Steering Committee

The Trans-NIH Angiogenesis Program (TARP) was established to do the following. (1) Encourage and facilitate the study of the underlying mechanisms controlling blood vessel growth and development; (2) identify specific targets and to develop therapeutics against pathologic angiogenesis to reduce the morbidity due to abnormal blood vessel proliferation in a variety of disease states; (3) better understand the process of angiogenesis and vascularization to improve states of decreased vascularization; (4) encourage and facilitate the study of the processes of lymphangiogenesis; and (5) achieve these goals through a multidisciplinary approach, bringing together investigators with varied backgrounds and interests.

Participating Institutes and Centers: NICHD, NEI, NHLBI, NIDDK, and NINDS

Web site: http://www.tarp.nih.gov/index.html

35. Trans-NIH Bioethics Committee

This committee was established to contribute directly to NIH's policy development and decision-making process by serving as a forum for discussion and analysis on a range of issues related to the conduct and oversight of NIH-funded clinical research.

Participating Institutes and Centers: All NIH Institutes and Centers

Web site: http://crpac.od.nih.gov/tnbc.asp

36. Trans-NIH Biomedical Informatics Coordinating Committee

The Trans-NIH Biomedical Informatics Coordinating Committee was established in the spring of 2007 to improve communication and coordination of issues related to clinical and bio-informatics at NIH. The committee provides a forum for sharing information about NIH informatics programs, projects, and plans, including their relationship to activities of other Federal agencies and non-Government organizations. At the Director's request, it coordinates NIH's input into external informatics forums and initiatives, including those related to information technology standards development.

<u>Participating Institutes and Centers</u>: NIAID, CC, CIT, CSR, FIC, NCI, NCRR, NHGRI, NHLBI, NIAAA, NIAMS, NIBIB, NICHD, NIDCD, NIDDK, NIEHS, NIGMS, NIMH, NINDS, NINR, NLM, OER, Office of the Chief Information Officer, and OSPA

37. Trans-NIH Committee on Rare Diseases

The charge of this group is to develop an integrated NIH-wide plan for research in rare diseases that addresses basic, translational, and clinical aspects aimed at the prevention and cure of rare diseases.

Participating Institutes and Centers: All NIH Institutes and Centers

38. Trans-NIH Diabetes Complications Working Group

This working group meets to discuss the status of current projects and potential ideas for future projects about complications of diabetes mellitus.

Participating Institutes and Centers: NIDDK, NEI, NHLBI, and NIMH

39. Trans-NIH Endocrine Group

The Trans-NIH Endocrine Group meets once every two months to discuss topics related to endocrine research. The topics include scientific discussions on endocrine research and review and program issues, as well as facilitating extramural research in this area.

Participating Institutes and Centers: NIA, CSR, NCI, NIAAA, NICHD, and NIDDK

40. Trans-NIH Fragile X Research Group

The charge of this trans-NIH working group is to develop comprehensive recommendations for specific, high-priority research objectives for Fragile X Syndrome and associated disorders. The working group is composed of scientific experts from the research and clinical communities, along with representatives of affected individuals and family members, other pertinent Federal agencies and invested NIH Institutes and Centers. The recommendations are designed to be used by the NIH and research communities and to be shared with other Federal agencies to facilitate coordinated research activities that will lead to timely detection, diagnosis, treatment, and prevention of the targeted disorders.

Participating Institutes and Centers: NICHD, NCRR, NIA, NIDDK, NIMH, NINDS, and ORDR

<u>Web site</u>: http://www.nichd.nih.gov/publications/pubs_details.cfm?from=&pubs_id=5729

41. Trans-NIH Gene Therapy Committee

This trans-NIH committee was established to coordinate and exchange information on basic and clinical gene therapy studies supported by NIH Institutes and Centers.

Participating Institutes and Centers: NIAID, NCI, NCRR, NEI, NHLBI, NIDDK, and NINDS

42. Trans-NIH Global Health Research Working Group

The working group was established to explore, develop, and oversee specific actions NIH could take to support its Institutes' and Centers' international research engagements. The group meets quarterly and convenes advisory subgroups, as needed, to analyze issues and develop recommendations for individual Institutes and Centers or cross-NIH consideration.

<u>Participating Institutes and Centers</u>: NIA, CC, CSR, FIC, NCCAM, NCI, NCRR, NEI, NHGRI, NHLBI, NIAID, NIAMS, NIBIB, NICHD, NIDA, NIDCR, NIDDK, NIEHS, NIMH, NINDS, NLM, and OAR

Web site: http://www.fic.nih.gov/news/publications/global_health_matters/2009/1009_transnih.htm

43. Trans-NIH Hepatitis C Virus Working Group

The charge of this group is to develop an integrated NIH-wide plan for research in Hepatitis C Virus (HCV) that addresses basic, translational, and clinical aspects of HCV infection aimed at the prevention and cure of the disease.

Participating Institutes and Centers: NIDDK, CSR, NCI, NCRR, NHLBI, NIAAA, NIAID, and NIDA

44. Trans-NIH Lymphatic Disease Working Group

The goal of this trans-NIH group is to develop integrated NIH activities to enhance research in lymphatic diseases.

Participating Institutes and Centers: NHLBI, NCI, NEI, NIAID, NIDDK, NINR, and ORDR

45. Trans-NIH Nanotechnology Task Force

The task force was established in April 2006 as a coordinating body for nanoscience and nanotechnology activities across NIH. This group also serves as the locus for interaction with nanotechnology activities in other Federal agencies and for outreach to other stakeholders. The task force has representation from both intramural and extramural NIH staff.

<u>Participating Institutes and Centers</u>: FIC, CIT, CSR, DNRC, NCI, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIEHS, NIGMS, NIMH, NIMHD, NINDS, NINR, NLM, and OD

46. Trans-NIH Sarcoidosis Working Group

This group was established in 2004 to share and coordinate information on sarcoidosis research and to develop activities that might be jointly sponsored, including workshops and program announcements to highlight opportunities for research and collaborative projects. The group has annual meetings; the last was held in July 2010.

Participating Institutes and Centers: NHLBI, NEI, NHGRI, NIAMS, NIDDK, NIEHS, NINDS, NINR, ORDR, and ORWH

47. Trans-NIH Sleep Research Coordination Committee

This committee provides a forum for program officers in participating NIH Institutes and Centers to discuss sleep and circadian research and potential opportunities for programmatic coordination. The scope includes research, training, health information dissemination, and other activities with respect to sleep disorders, including biological and circadian rhythm research, basic understanding of sleep, chronobiology, and other sleep-related research.

Participating Institutes and Centers: NHLBI, NCI, NCRR, NIA, NIAAA, NICHD, NIDA, NIDDK, NIMH, NINDS, NINR, OBSSR, and ORWH

48. Trans-NIH Traumatic Brain Injury Work Group

This work group was initiated to review and develop NIH activities regarding research into the assessment, consequences, and treatment of traumatic brain injury.

Participating Institutes and Centers: NIDA, NCRR, NHLBI, NIA, NIAAA, NIBIB, NICHD, NIGMS, NIMH, NINDS, and OD

49. Trans-NIH Tuberous Sclerosis Complex Working Group

This group brings together NIH staff working in programs relevant to the biology and treatment of Tuberous Sclerosis Complex (TSC) with patient advocacy groups (e.g., TS Alliance) and other Federal agencies with programs in TSC. The goal of the group is to share advances in understanding disease pathology and treatment strategies and to identify opportunities to support activities that will further advance the fight against this devastating disease.

Participating Institutes and Centers: NINDS, NCI, NHLBI, NIAMS, NICHD, NIDDK, NIMH, and ORDR

50. Trans-NIH Web Material Transfer Agreement Project

This working group is focused on the development of an NIH-wide Web-based workflow management and database system to facilitate the rapid location of biological materials that can be shared from NIH laboratories and allow for near-instantaneous material transfer agreement turnaround time. Further, the system should provide novel metrics related to materials and investigators' transfer patterns.

Participating Institutes and Centers: All NIH Institutes and Centers

51. Trans-NIH Women's Health Research Group

The Trans-NIH Women's Health Research Group is organized to support and encourage research in women's health issues at the basic, translational, and clinical levels to include the biology and diseases status of different organ systems. The group organizes a monthly symposium series and a mentoring program for fellows supported to perform research studies focusing on women's health diseases.

Participating Institutes and Centers: NIEHS, NCI, NEI, NHLBI, NICHD, NIDDK, NLM, and ORWH

52. Trans-NIH Working Group on Global Diabetes Research

In addition to developing a research agenda on global diabetes research, this group also focuses on bridging the gap between researchers and other stakeholders to promote the application of the latest evidence-based interventions in diabetes care and control policies for the developing world.

Participating Institutes and Centers: FIC, NEI, NHGRI, NIAID, NICHD, NIDDK, and NIMHD

53. Trans-NIH Working Group on Global Health and Climate Change

The working group develops an NIH-wide research agenda for climate and health for dissemination among scientific journals, public lectures, and other venues in anticipation of requests from the current Administration and Congress for such a plan.

<u>Participating Institutes and Centers</u>: FIC, NCI, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDCR, NIEHS, NIMH, NIMHD, NLM, and OD

54. Trans-NIH Zebrafish Coordinating Committee

The committee was established in 1997 to promote the use of zebrafish to study vertebrate development and disease. The initiatives include NIH-sponsored courses and meetings, zebrafish genomic and genetic resources, selected reports and publications, and research initiatives.

Participating Institutes and Centers: NCI, NEI, NHLBI, NIA, NIAAA, NIAMS, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIEHS, NIGMS, NIMH, and NINDS

Web site: http://www.nih.gov/science/models/zebrafish/

55. Working Group on Eukaryotic Pathogens and Disease Vectors Target Selection

This working group promotes and coordinates international, collaborative efforts to accelerate research and development of genetic resources in infectious diseases by identifying high priority eukaryotic pathogens and invertebrate vectors of diseases. The working group drafted white papers to support sequencing of identified high priority organisms.

Participating Institutes and Centers: NHGRI and NIAID

III. Educational Campaigns and Clearinghouses

1. AIDSinfo

This effort offers the latest U.S. Federal Government-approved information about HIV/AIDS medical practice guidelines and clinical trial research in treatment and prevention for health care providers, researchers, people affected by HIV/AIDS, and the general public. The medical practice guidelines are developed by working groups under the auspices of the Office of AIDS Research Advisory Council. These working groups include pharmacists, physicians, researchers, and HIV treatment advocates from across the country. InfoSIDA, a Spanish-language version, features a customized Home page and Spanish language services, including live health online.

Participating Institutes and Centers: NLM, NIAID, and OAR

2. "Are You at Risk for Oral Cancer? What African American Men Need to Know"

This campaign is designed to promote early detection of oral cancer among African American men who have the highest oral cancer incidence and the lowest survival rate compared to any other group in the United States. A new video and three radio public service announcements were released in FY 2010 to coincide with National Minority Cancer Awareness Week (April 18-24, 2010). The video, also available on the NIH YouTube channel, will be promoted via an online press release.

Participating Institutes and Centers: NIDCR and NCI

<u>Web site</u>: <u>http://www.nidcr.nih.gov/OralHealth/Topics/OralCancer/AfricanAmericanMen.htm</u>

3. Children and Clinical Studies Educational Web Resource

This resource is a Web-based educational tool designed to equip parents and children with the information they need to understand clinical research and make informed decisions about participating in a pediatric study. The site combines text, graphics, and documentary films of experts, parents, and children sharing their experiences with pediatric clinical research.

Participating Institutes and Centers: NHLBI, NCRR, and NICHD

Web site: http://www.nhlbi.nih.gov/childrenandclinicalstudies/index.php

4. ClinicalTrials.gov

This is a public resource of information on clinical research, offering up-to-date information on over 99,000 federally and privately supported clinical studies on a wide range of diseases and conditions. Studies listed in the database are conducted in all 50 States and in 174 countries. ClinicalTrials.gov currently contains registration information for more than 77,000 trials sponsored by NIH, other Federal agencies, and private industry. Reporting of results is required for certain studies of approved FDA-regulated drugs, biological products, and devices. There are currently over 2,300 studies with results posted in ClinicalTrials.gov.

<u>Participating Institutes and Centers</u>: NLM, CC, NCCAM, NCI, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIEHS, NIGMS, NIMH, NINDS, NINR, and OD

Web site: www.ClinicalTrials.gov

5. MedlinePlus and MedlinePlus en Español

MedlinePlus and MedlinePlus en español are health information portals that bring together NIH and other Government and authoritative health information for patients, families, and professionals. MedlinePlus links to over 5,800 consumer health Web documents in English, and almost 8,000 in Spanish, from nearly every NIH Institute and Center.

<u>Participating Institutes and Centers</u>: NLM, CC, NCCAM, NCI, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIEHS, NIGMS, NIMH, NIMHD, NINDS, NINR, and OD

Web site: http://medlineplus.gov, http://medlineplus.gov/salud

6. National Asthma Control Initiative

The National Asthma Control Initiative (NACI) is a multicomponent initiative that engages diverse stakeholders who are concerned about or involved in improving asthma control. Its goal is to bring the asthma care that patients receive in line with evidencebased recommendations from two reports published by the National Asthma Education and Prevention Program: *Guidelines for the Diagnosis and Management of Asthma* and *Guidelines Implementation Panel Report—Partners Putting Guidelines Into Action*. The NACI is bringing together organizations from local, State, regional, and national levels so that they can share best practices, pool and direct resources, and identify new directions and learning opportunities.

Participating Institutes and Centers: NHLBI, NIAID, and NIEHS

7. National Eye Health Education Program Partnership

The partnership was established by NEI to promote collaboration on eye health education for higher risk audiences, including people with diabetes, people over age 60, and people with a family history of eye disease.

Participating Institutes and Centers: NEI, NIA, and NIDDK

Web site: http://www.nei.nih.gov/nehep

8. National Kidney Disease Education Program

The National Kidney Disease Education Program (NKDEP) is an NIH initiative designed to reduce the morbidity and mortality caused by kidney disease and its complications. NKDEP aims to improve early detection of chronic kidney disease (CKD), facilitate identification of patients at greatest risk for progression to kidney failure, promote evidence-based interventions to slow progression of CKD, and support the coordination of Federal responses to CKD.

Participating Institutes and Centers: NIDDK and NHLBI

Web site: http://www.nkdep.nih.gov/

9. Neuroimaging Informatics Tools & Resources Clearinghouse

The Neuroimaging Informatics Tools & Resources Clearinghouse (NITRC) program consists of a Web site, associated communications tools, and scientific and administrative support personnel that foster the neuroimaging informatics community and enable the dissemination and sharing of existing tools and resources. The NITRC program was motivated by the recognition that NIH has supported the development of sophisticated, high-quality neuroimaging informatics tools and resources but that the value of these tools and resources is only fully realized with their wide-spread adoption.

<u>Participating Institutes and Centers</u>: NCCAM, NCRR, NEI, NIA, NIAAA, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIEHS, NIGMS, NIMH, NINDS, NINR, and OBSSR

Web site: http://www.nitrc.org/

10. NIH Osteoporosis and Related Bone Diseases—National Resource Center

This clearinghouse produces and distributes health education materials to patients, health professionals, researchers and scientists, voluntary and professional organizations, and the media. It provides resources and information on metabolic bone diseases, including osteoporosis and osteogenesis imperfecta. A new Web site was launched in August 2010 as a one-stop information source. It includes the popular, interactive Web tool, *Check Up On Your Bones*, which provides bone health information for people of all ages and gives a personalized strategy to help make bones stronger and healthier.

Participating Institutes and Centers: NIAMS, NIA, NICHD, NIDCR, NIDDK, and ORWH

Web site: http://www.niams.nih.gov/Health_Info/Bone/default.asp

11. NIH Public Trust Initiative

The mission of this initiative is to enable the public to understand and to have full confidence in the research that NIH conducts and supports across the country and throughout the world. Specifically, the initiative seeks to provide the public information about how NIH conducts and supports research; opportunities to participate in priority setting and other NIH activities; opportunities to participate in clinical research; and access to, and understanding of, research results.

<u>Participating Institutes and Centers</u>: NINR, CC, FIC, NCCAM, NCI, NCRR, NIA, NIAAA, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIGMS, NIMH, NINDS, OD, and ORWH

Web site: http://publictrust.nih.gov

12. NIHSeniorHealth.gov

This senior-friendly Web site is specially formatted for optimal use by seniors seeking health information. It features health information on a variety of topics pertinent to older adults and includes videos, interactive quizzes, and FAQs to reinforce learning on the Web.

<u>Participating Institutes and Centers</u>: NIA, NCCAM, NCI, NEI, NHLBI, NIAID, NIAMS, NIDA, NIDCD, NIDCR, NIDDK, NIGMS, NIMH, NINDS, and NLM

13. SciLife

SciLife is an annual event that provides free information, resources, and organizational tools to help high school students and their parents plan for college and explore career options in the health and medical sciences. NIH joins forces with area leaders in science education to offer the program to people in the Washington, D.C., metropolitan area.

Participating Institutes and Centers: NHGRI, NIAID, NIDDK, and OSE

14. Trans-NIH American Indian and Alaska Native Health Communications and Information Work Group

The work group, which includes health education and communications staff from across NIH, has formed a partnership with the Indian Health Service to disseminate NIH health information to approximately 1,700 community health representatives.

Participating Institutes and Centers: NIAMS, NCI, NCRR, NEI, NHGRI, NHLBI, NIA, NICHD, NIDA, NIDCR, NIDDK, NLM, and ORWH

Web site:

http://www.niams.nih.gov/about_Us/Mission_and_Purpose/Community_Outreach/Multic ultural_Outreach/AIAN_WG/default.asp

15. We Can! "Ways to Enhance Children's Activity and Nutrition"

We Can! is a national program designed for families and communities to help children maintain a healthy weight.

Participating Institutes and Centers: NHLBI, NCI, NICHD, and NIDDK

Web site: http://www.nhlbi.nih.gov/health/public/heart/obesity/wecan/index.htm

Appendix 3: Key to Abbreviations

AHRQ - Agency for Healthcare Research and Quality, HHS

CC – Clinical Center, NIH

- CDC Centers for Disease Control and Prevention, HHS
- CDER Food and Drug Administration Center for Drug Evaluation and Research, HHS
- CIT Center for Information Technology, NIH
- CMS Centers for Medicare and Medicaid Services, HHS
- CSR Center for Scientific Review, NIH
- DNRC Division of Nutrition Research Coordination, OD, NIH
- DOD U.S. Department of Defense

DPCPSI – Division of Program Coordination, Planning, and Strategic Initiatives, OD, NIH

- FDA Food and Drug Administration, HHS
- FIC Fogarty International Center, NIH

HHS - U.S. Department of Health and Human Services

HRSA - Health Resources and Services Administration, HHS

- IC NIH Institute or Center
- NCCAM National Center for Complementary and Alternative Medicine, NIH
- NCI National Cancer Institute, NIH
- NCRR National Center for Research Resources, NIH
- NEI National Eye Institute, NIH
- NHGRI National Human Genome Research Institute, NIH
- NHLBI National Heart, Lung, and Blood Institute, NIH
- NIA National Institute on Aging, NIH
- NIAAA National Institute on Alcohol Abuse and Alcoholism, NIH
- NIAID National Institute of Allergy and Infectious Diseases, NIH
- NIAMS National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH
- NIBIB National Institute of Biomedical Imaging and Bioengineering, NIH

NICHD – *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, NIH

- NIDA National Institute on Drug Abuse, NIH
- NIDCD National Institute on Deafness and Other Communication Disorders, NIH
- NIDCR National Institute of Dental and Craniofacial Research, NIH

- NIDDK National Institute of Diabetes and Digestive and Kidney Diseases, NIH
- NIEHS National Institute of Environmental Health Sciences, NIH
- NIGMS National Institute of General Medical Sciences, NIH
- NIMH National Institute of Mental Health, NIH
- NIMHD National Institute on Minority Health and Health Disparities, NIH
- NINDS National Institute of Neurological Disorders and Stroke, NIH
- NINR National Institute of Nursing Research, NIH
- NIST National Institute of Standards and Technology, U.S. Department of Commerce
- NLM National Library of Medicine, NIH
- NSF U.S. National Science Foundation
- OAR Office of AIDS Research, DPCPSI, OD, NIH
- OBSSR Office of Behavioral and Social Sciences Research, DPCPSI, OD, NIH
- OCPL Office of Communications and Public Liaison, OD, NIH
- OD Office of the Director, NIH
- ODP Office of Disease Prevention, DPCPSI, OD, NIH
- ODS Office of Dietary Supplements, ODP, DPCPSI, OD, NIH
- OER Office of Extramural Research, OD, NIH
- OIR Office of Intramural Research, OD, NIH
- OLPA Office of Legislative Policy and Analysis, OD, NIH
- OM Office of Management, OD, NIH
- ORDR Office of Rare Diseases Research, ODP, DPCPSI, OD, NIH
- ORS Office of Research Services, OM, OD, NIH
- ORWH Office of Research on Women's Health, DPCPSI, OD, NIH
- OSE Office of Science Education, OSP, OD, NIH
- OSP Office of Science Policy, OD, NIH
- OSPA Office of Science Policy Analysis, OSP, OD, NIH
- OTT Office of Technology Transfer, OIR, OD, NIH
- SAMHSA Substance Abuse and Mental Health Services Administration, HHS
- USAID U.S. Agency for International Development
- USDA U.S. Department of Agriculture
- VA U.S. Department of Veterans Affairs