Diabetes Mellitus Interagency Coordinating Committee (DMICC) Expanding Collaborations to Translate Research into Practice

> Neuroscience Building, Conference Room C 6001 Executive Boulevard, Rockville, MD 12:30pm-4:15pm April 1, 2008

WELCOME AND GOALS OF THE MEETING

Dr. Judith Fradkin, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Update on the DMICC

Dr. Fradkin welcomed participants to the meeting and updated Committee members on several issues. First, as the NIDDK works toward making all materials posted on their website 508 compliant, PowerPoint presentations from previous DMICC meetings have been removed from the website. The NIDDK is currently trying to enhance the communication strategy of the DMICC, including redesigning the DMICC website in order to promote the activities of the Committee and to make information more accessible to the broader community. In addition, the NIDDK will be developing a brochure to highlight and record the activities and accomplishments of the DMICC in a user-friendly manner. Members are encouraged to share their suggestions and thoughts about showcasing the DMICC with the chair. To broaden the Committee's membership, the NIDDK has invited the Department of Defense and the Department of Agriculture to provide representatives of their agencies to the Committee.

Special Funding Programs for Type 1 Diabetes Research and for American Indians

The Special Statutory Funding Program for Type 1 Diabetes Research and the Special Diabetes Program for Indians have been extended for an additional year through FY 2009 at a level of \$150 million each. Because it is challenging to most effectively use the funds in a single year with the typical NIH funding mechanisms, the NIDDK, which oversees the Special Funding Program for Type 1 Diabetes Research, has received NIH approval for a new multiyear funding mechanism called the DP3. For FY 2009, this funding mechanism will be used to solicit applications focused on two particular areas of type 1 diabetes research: (1) the mechanisms of increased vascular permeability that underlie many of the complications of type 1 diabetes; and (2) the newly discovered type 1 diabetes genes and the mechanisms by which they cause susceptibility to disease. Additionally, the NIDDK has organized an evaluation meeting on April 29-30, 2008, for an external panel of scientific experts to review the clinical research efforts supported by the Special Type 1 Diabetes Funding Program and to guide future efforts of these ongoing programs.

Goals of Today's Meeting

Dr. Fradkin noted that today's meeting focuses on collaboration and asked that speakers direct their presentations to potential opportunities at their agency or institute which could involve the participation of other DMICC member agencies.

SPECIAL DIABETES PROGRAM FOR AMERICAN INDIANS: MAXIMIZE OPPORTUNITIES TO IMPROVE DIABETES CARE AND PREVENTION

Dr. Kelly Acton, Indian Health Service

Dr. Acton presented the Canadian Institutes of Health Research's (CIHR) Office of Knowledge Translation (KT) program as a model for translating scientific discoveries into public health, and highlighted ways for DMICC members to participate in the process. In the CIHR KT system, end users are encouraged to "take ownership" of scientific research, adapting the knowledge for local use. (Information on CIHR terms and definitions can be found at the CIHR Knowledge Translation website: http://www.cihr-irsc.gc.ca/e/29418.html)

In applying the CIHR experience, the IHS effort recognizes the significant respects in which the Indian community differs from other groups and where it does not. Such characteristics help to determine when a scientific finding requires cultural adaptation. The IHS collaborates with the scientists whose findings are adapted to craft prevention and intervention tools. The IHS has also recently partnered with the Institute for Healthcare Improvement to learn how to improve the system of care for their patients.

Based on the CIHR model, Dr. Acton suggested that agencies or institutes that translate the knowledge into practice (like the IHS) could collaborate with research agencies in shaping the research questions, deciding on the methodology, developing tools, collecting data and designing the research studies. Such collaborations may be of benefit when the need arises to apply and disseminate study results. She went on to suggest that every relevant randomized controlled trial be designed with a view to end-of-study translation activities. Federal agencies that have relevant research findings or an interest in translating materials for the Indian community should contact the IHS to put this principle into practice.

Dr. Fradkin noted that the first NIDDK-supported Research Demonstration and Dissemination Projects for Diabetes Prevention and Control (R18 grants) are now being completed. These projects focus on translating the results of the Diabetes Prevention Program and other diabetes clinical trials to real world settings. She suggested that the success of these projects should be evaluated in terms of dissemination and uptake by potential end users. These projects also provide an opportunity for collaboration--agencies such as the IHS and VA could be involved in generating feedback and be made aware of these studies. Dr. Acton indicated that conferring with the researchers themselves is extremely helpful in the translation process and Dr. Albright pointed out that these conversations can also be beneficial in identifying opportunities for future research.

Dr. Ashley noted that HHS is planning a summit regarding diabetes and Pacific Island tribes; IHS, NIDDK, and HRSA are all involved in the planning.

COMMUNITY PARTNERSHIPS FOR EVIDENCE-BASED SOLUTIONS

Dr. Ann Albright, Centers for Disease Control and Prevention

Dr. Albright noted that the CDC has worked with IHS, HRSA and NIH on studies and to disseminate information to the public. She also discussed the Diabetes Primary Prevention

Initiative (DPPI), a partnership between the CDC, the National Association of Chronic Disease Directors, AHRQ, and state diabetes programs in five states to follow up on the results of the Diabetes Prevention Program. The DPPI focuses on surveillance, system dynamic modeling, and interventions and will help to determine where the CDC can collaborate with states on primary prevention. Dr. Albright encouraged DMICC members to highlight opportunities for partnerships, if they have people stationed at the state level. She also stated that there are opportunities for DMICC members to collaborate with CDC on the development of the next phase of CDC's primary prevention work (both research and public health programming). She noted that a primary prevention meeting summit is being planned with colleagues at Indiana University; Dr. Albright encouraged DMICC members interested in the meeting or in having a role in the planning to contact her.

Dr. Barbara Bartman, Agency for Healthcare Research and Quality

Dr. Bartman outlined several ongoing AHRQ-led partnerships with opportunities for further collaboration. These included: the National Healthcare Quality and Disparities Report (NHQR), which is the product of collaboration among agencies across DHHS; the Improving Hispanic Elders Health program, a translational project that partners five HHS agencies (Agency on Aging, AHRQ, CDC, CMS and HRSA) to assist local communities in developing coordinated strategies for improving the health and well-being of elderly Hispanics; the John M. Eisenberg Clinical Decisions and Communications Science Center at Oregon Health & Science University, which is developing tools to help people make decisions about health care and translating research information; and the Medicaid Care Management Learning Network, which provides opportunities for collaboration with HRSA, CDC and CMS.

Dr. Sheila Roman, Centers for Medicare and Medicaid Services

Dr. Roman described the CMS demonstration projects as particularly suited for collaboration with other agencies represented on the DMICC. Dr. Roman indicated that the CMS Office of Research Development and Information (ORDI) would be open to collaboration in the design and development of these demonstration projects. She encouraged DMICC members to visit the ORDI website (http://www.cms.hhs.gov/ResearchGenInfo/) for information on specific demonstration projects in order to facilitate collaboration. In addition, CMS is a repository for a large amount of administrative data which can be used by DMICC member agencies to identify areas and communities in need of knowledge translation. Dr. Roman reviewed several past CMS collaborations with other DMICC member agencies, including AHRQ, CDC, VA, and NHLBI.

Dr. Roman discussed CMS reports, which could also be opportunities for collaborations between CMS and DMICC member agencies. These include value-based purchasing programs, the Physician Quality Reporting Initiative, the Hospital Acquired Conditions project, and the Quality Improvement Organization Program (QIO). There are many possibilities for QIO collaborations concerning diabetes self-management training as an intervention, design and community partnerships, and data evaluation.

Dr. Tanya Pagan Raggio Ashley, Health Resources and Services Administration

Dr. Ashley provided several examples of collaborations between HRSA and other DMICC member agencies. For example, HRSA collaborates in the sharing of educational materials with NIDDK, CDC, CMS, AHRQ, and IHS; and in the translation of research into practice with

NIDDK and AHRQ. The Hispanic Elderly project is a collaboration between HRSA, AHRQ, CMS and CDC. HRSA also collaborates with other DMICC member agencies on the U.S. Preventative Task Force (AHRQ), National Health Service Corps and tribal consultation (IHS), the State Diabetes Programs (CDC), and Medicare/Medicaid funding (CMS).

Dr. Ashley highlighted several areas for future collaborations between HRSA and other DMICC member agencies, including prevention intervention efforts focusing on overweight and obese patients, on earlier identification and treatment of diabetes to prevent complications, and on severely underserved populations with high prevalence of diabetes and complications (e.g., Pacific Islanders). There are also opportunities to collaborate on innovative practices with the health centers and through the Center for Quality which will be gathering more agency-wide information on diabetes outcomes via HbA1C.

Discussion

Dr. Fradkin inquired about the best way to make use of existing databases to structure community-based research and to assess and test intervention campaigns. Dr. Albright responded that it is difficult to assess small populations by using larger population based data sets. It is necessary, then, to look at data specific to particular interventions and to improve smaller data sets for the larger population based work. Therefore, it might be advantageous to look at the communities in which agencies already have programs when planning and developing new initiatives.

Dr. Albright expressed hope that the DMICC could be a forum for discussing where in the evolution in the development of projects would be the best time to vet collaborations with other DMICC member agencies. Could agencies come in with new ideas versus asking other DMICC member agencies to join projects that are already fully developed? In other words, it may be beneficial for DMICC members to have discussions during the idea-generating stage of a project, rather than when projects are fully developed. This approach could help to promote and maximize interagency coordination. Dr. Fradkin noted that this approach could be useful for CMS demonstration projects related to diabetes, with DMICC member agencies working with CMS in the initial design of these projects. Dr. Roman responded that there is the opportunity to provide input for CMS demonstration projects and in the evaluation process. She encouraged DMICC member agencies to monitor CMS statues related to their areas of interest.

Dr. Parks (FDA) inquired about a role for the FDA in generating a database of patient populations from drug trials. Dr. Acton replied that there would be interest from IHS and that the Tribal Leaders Diabetes Committee could discuss this possibility.

Finally, Dr. Bartman noted that AHRQ and FDA fund the Centers for Education and Research on Therapeutics (CERTs) which includes the HMO Research Network, whose goal is to develop a distributive network using registries as well as electronic medical records. She pointed out that there is potential to obtain a significant sample size to do case control studies that are condition specific from this database. Dr. Fradkin remarked that as HMOs lead the way with electronic medical records, the records could potentially be useful for answering questions about long-term outcomes with regard to pharmaceuticals that are not addressed in clinical trials.

Opportunities for Inter-Agency Collaborations with CMS on Diabetes Data Analysis

Dr. Sheila Roman, Centers for Medicare and Medicaid Services

Dr. Roman indicated that there are opportunities for collaborations with CMS on diabetes data analysis and discussed three databases that may be of interest to DMICC member agencies: (1) the Chronic Condition Data Warehouse (http://www.ccwdata.org); (2) the Medicare Current Beneficiary Survey (http://www.cms.hhs.gov/MCBS/); and (3) the Medicare Quality Monitoring System (http://www.cms.hhs.gov/QualityInitiativesGenInfo/15_MQMS.asp).

Dr. Fradkin expressed an interest in presenting information about these databases to the scientific community. She suggested that it may be useful to organize a joint workshop or DMICC-sponsored meeting to make the academic community (e.g., epidemiologists) aware of these CMS databases in addition to CDC databases and NIH repositories. Dr. Roman indicated that the availability of the databases will be announced at the upcoming annual meeting of AcademyHealth (www.academyhealth.org/arm/index.htm), which brings together health services researchers and providers. She will pass Dr. Fradkin's suggestions on to the CMS Office of Research Development and Information.

The Hispanic Community Health Study

Dr. Larissa Avilés-Santa, National Heart, Lung, and Blood Institute

Dr. Avilés-Santa discussed The Hispanic Community Health Study / Study of Latinos (HCHS/SOL; http://www.cscc.unc.edu/hchs/), a multi-center epidemiologic study in Hispanic/Latino populations in the U.S. to identify the prevalence of and risk factors for cardiovascular disease and other conditions and to determine the role of ethnicity and culture in health and disease. The HCHS is relevant to DMICC member agencies because it is: (1) collecting basic information about diabetes and its complications; (2) collecting information on utilization of health resources and their availability; and (3) addressing the need for materials to be culturally translated and appropriate. Dr. Avilés-Santa encouraged DMICC member agencies to use this study as an opportunity to develop and test instruments for research and health services relevant to Hispanic/Latino cultures.

Discussion and Review of Potential Collaborations

Dr. Judith Fradkin, National Institute of Diabetes and Digestive and Kidney Diseases

Dr. Fradkin noted that the DMICC is transitioning toward being a more collaborative organization where members are able to hear about projects in their early stages so that interested member agencies can get involved. The members discussed how to: collaborate more effectively, best use the in-person meeting times, decide upon meeting topics, and balance the different missions and interests of the participating agencies.

The members also discussed ways in which the DMICC can be more proactive in describing their mission and successes to the public. Members agreed that a document illustrating the achievements of the DMICC and how the different agencies complement each others' efforts would be beneficial. Toward that end, Dr. Mary Hanlon and Dr. Julie Wallace of the NIDDK

Office of Scientific Program and Policy Analysis will be developing a promotional brochure for the DMICC. At the next meeting, they will present a proposed outline and their anticipated needs from DMICC member agencies.

Finally, Dr. Fradkin proposed a future workshop, hosted by the DMICC, to increase awareness of the governmental databases available for use by the scientific research community (e.g., CMS databases).