

# Research Translation, Dissemination, and Application— Moving Toward a New Vision and Strategic Framework

Discussion and Consensus Findings

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# **Core Meeting Objective**

To begin the process of creating a new vision and strategic plan for the future to enhance research translation and dissemination of the science and thereby achieve greater reductions in cardiovascular disease (CVD) risk in the United States and throughout the world.

# **Synopsis of Discussion Topics**

#### 1. Risk-Factor Programs Versus Overarching CVD Program

Looking at the National Heart, Lung, and Blood Institute's (NHLBI's) current national education programs and other initiatives, should these risk-factor programs and the clinical guidelines remain separate with their own unique identities? Or should consideration be given to the integration of risk-factor programs into an overarching CVD education program?

#### 2. Enhancing Dissemination of NHLBI-Funded Research

In light of the significant lag time of 15–20 years between initial release of research findings and their widespread utilization to improve public health, are there means to expedite this process through the development of new and expanded roles for NHLBI, grantees, patient groups, and other agencies and organizations?

# 3. Putting Research Into Action Through Broadened Stakeholder Collaboration and Knowledge Exchange

Can research evidence be more successfully disseminated through horizontal collaboration between the "siloed" worlds of researchers, practitioners, policymakers, and patients? What are the untapped ways and partnership models that can facilitate this collaboration?

Note: Detailed background on the three discussion topics is contained in Appendix C.

# **Thought Leaders' Essential Recommendations**

The NHLBI should:

- Maintain risk-factor-specific clinical guidelines.
- Establish an entity or process to integrate the science and clinical recommendations regarding CVD for practicing physicians, patients, and the community.
- Leverage more effectively the resources of stakeholders to support the translation and dissemination of the science.
- Collaborate broadly with other agencies and organizations in order to achieve the critical mass required for significant change.

# Synopsis of Thought Leaders' Findings

Note: Discussion of each of the three topic areas often overlapped.

## 1. Risk-Factor Programs Versus Overarching CVD Program

- **Guidelines.** Risk-factor-specific guidelines and maintenance of the science base for each risk factor were deemed *critical*. This was due to the necessity of bringing to the table the specialized expertise required to evaluate and synthesize the science, the vast body of literature, and the ability to develop clinical guidelines for each risk factor. The discrete risk-factor guidelines were also viewed as crucial in that they serve as a scientific foundation and a respected and credible standard of care throughout the world.
- **National Programs.** National CVD programs dedicated to individual risk factors and acute events were seen as very important by a number of participants (especially those who had worked directly with the programs); however, *the focus by a majority seemed to be on the guidelines per se*—which were often referred to as NIH or NHLBI guidelines.
- **Integration.** Virtually all of the participants saw a pressing *need for some process or entity* to integrate the science concerning CVD. This need was seen as important especially because:
  - Patients typically present with multiple risk factors.
  - o An integrative approach is required by definition to treat the metabolic syndrome.
  - o The lifestyle issues extend across all the risk factors.
  - o There is a need to focus on specific populations, such as the pediatric age group.
  - Prevention of the risk factors, assessment of cardiovascular risk, and the need for better adherence cut across all the risk factors.
  - The disciplines are increasingly coming together and tending toward a holistic approach to medicine.
  - o The guidelines often compete with and influence each other.
  - The practicing provider is busy and is often overwhelmed and cannot follow complex individual guidelines.
  - o Genetic mapping is resulting in the emergence of personalized medicine.
  - Patients are confused by multiple guidelines coming from various organizations, especially as reported through the media.
- Nature of Integration. This integrative function was posited by many discussants as:
  - Simplified integrative CVD prevention and treatment guidelines for the community, practicing physician, and patient.
  - An integrative CVD program or function that would involve the convening of a group with broader representation to provide consistent direction to clinicians, patients, and the public.
  - An issue of systems and policy change primarily at the clinical and community level.

## 2. Enhancing Dissemination of NHLBI-Funded Research

For this topic area, the ideas expressed in the group tended to be more disparate, but the essential message was that the research findings are there, both clinical and behavioral, to improve public health. The NHLBI needs to use its stature and resources to collaborate with grantees and other organizations to translate and disseminate this science more effectively.

- There was unanimous agreement that the science does little good unless it is effectively translated and disseminated to health professionals, patients, the community, and other institutions.
- It was questioned whether or not grantees were equipped to do dissemination in an effective manner without assistance.
- In turn, it was suggested that a core center be established within NHLBI that would assist investigators in translating and disseminating their findings—not only for the major studies but also for the smaller ones.
- Similarly, the Rapid Early Action for Coronary Treatment (REACT) study was offered as an
  excellent model for the dissemination and implementation of the science in two ways:
  - As a study where the investigators and NHLBI staff worked together to activate communities and providers and to influence systems to reach the study's objectives (in this case, patients' delay in the initiation of heart attack therapy), and
  - As an example of NHLBI's reconfiguring and packaging the findings for dissemination to a broader audience of providers and public health personnel.
- Participants emphasized the need for better dissemination and utilization—not only of clinical research but also of the large body of behavioral research that already exists—as well as a need for additional behavioral research.
- They also saw the need for simplicity of information and for consistent messages that would be promulgated by all health agencies and organizations (this view was reiterated in the comments made in relation to stakeholder collaboration).
- They emphasized that dissemination involved the effort to affect complex adaptive systems at all levels (community, health systems, physicians' offices, schools, patients' families) in order to achieve sustainable change.
- It was recognized that NHLBI could not accomplish dissemination and thus affect
  communities and providers by itself. NHLBI needs to leverage the resources of other
  groups and develop a broad collaborative structure that could realistically accomplish major
  shifts in population health.

# 3. Putting Research Into Action Through Broadened Stakeholder Collaboration and Knowledge Exchange

The need for strategic collaboration by NHLBI with a broad range of stakeholders was considered imperative to be able to bring about significant change at all levels of the society.

- Participants felt that for NHLBI to have any hope of effectively competing with industry to get its messages out and its guidelines followed, it should:
  - o Be strategic and use its stature and credibility to partner strategically at all levels.
  - o Enlist a broad consortium of groups with similar goals that, despite not having the

- resources of industry, would have enough critical mass to allow it to have an impact on the population.
- Partner and leverage resources strategically through this consortium with organizations such as the American College of Cardiology (ACC), American Heart Association (AHA), American Diabetes Association (ADA), Centers for Disease Control and Prevention (CDC), and other NIH Institutes.
- Work with the Health Resources and Services Administration (HRSA), State departments of health, and Centers for Medicare and Medicaid Services (CMS), especially in regard to reducing health disparities.
- Learn to develop and frame its messages and guidelines so that they cannot be easily distorted by industry and others.
- Some participants felt that NHLBI could productively partner with industry and trade groups
  if it were careful and strategic in doing so, keeping in mind that NHLBI guidelines do also
  influence industry.
- Participants proposed that, to achieve significant change, NHLBI develop a far-reaching and challenging goal that, for example, would aim to have 90 percent of the population under control for the risk factors within 10 years.

# Overview of the Thought Leaders' Discussion and Advice

## Opening of the Session

The Thought Leaders Meeting was co-chaired by Elizabeth Nabel, M.D., Director of the NHLBI, and Daniel Jones, M.D., Associate Vice Chancellor for Health Affairs and Dean of the School of Medicine at the University of Mississippi Medical Center.

Dr. Nabel opened the session by commenting that the meeting was "an historic event" in that it was the first time in recent memory that such a broad array of thought leaders had been convened by the NHLBI to offer advice and counsel. She stated that it was time we looked at "our education, dissemination, and guideline programs in the Institute." Although these programs—the National High Blood Pressure Education Program (NHBPEP), National Cholesterol Education Program (NCEP), National Heart Attack Alert Program (NHAAP), and NHLBI Obesity Education Initiative (OEI)—"had been very successful over the years," they had tended to become "silos." Thus, the question was "had there been enough horizontal integration between them" and should the Institute think about approaching its programs differently?

Dr. Nabel added that what she hoped would come out of the meeting—what would be "helpful to the Institute at the end of the day"—would be some direction as to:

- Recommended dissemination processes and products of the Institute;
- Information that should be delivered to communities, patients, NHLBI's constituents, and the general public; and
- Committee structure for developing guidelines, developing messages, and carrying on other education activities.

She emphasized that although the NHLBI obviously supports research, it also has a mandate from Congress to translate and disseminate the research findings.

Dr. Jones, who facilitated the meeting, began by thanking Dr. Nabel for convening the meeting. He said he hoped the participants would speak their minds and do "some large thinking."

Dr. Jones then reviewed the three topic areas and opened the floor for discussion of the first topic area.

## Topic I: Risk-Factor Programs Versus Overarching CVD Program

The first participants to speak, Drs. Marvin Moser, Keith Ferdinand, and James Atkins, felt that the education programs were enormously successful because they were able to focus on "discrete entities rather than on a jumble of risk factors." Dr. Moser attributed the progress that had occurred in controlling and treating high blood pressure (HBP) and raising awareness in large part to the efforts of the NHBPEP as an independent program. The importance of the Joint National Committee HBP guidelines were pointed to as a standard that provided support for evidence-based medicine. In addition, Dr. Atkins emphasized, to effectively develop guidelines the right expertise must be at the table to address independently each risk factor.

The next speaker, Dr. Luther Clark, agreed that individual guidelines had been important in bringing the science together and developing strategies specific to each risk factor, but he added that "patients tend to be individuals with a multitude of problems." He stated that what was missing, "what we *don't* have," is a process to integrate the guidelines and develop strategies for approaching patients with multiple risk factors.

The comments that followed, although varied, all strongly echoed this same theme: keep the risk-factor guidelines but establish an integrative process or entity. A sampling of these comments follows:

Dr. Richard Schuster: "The Federal guidelines are paramount...[but] the guidelines now compete with each other, they influence each other....To say that the guidelines need to be independent, I'm afraid, is too simple a response for the practicing physician and the patient with multiple risk factors....We need to keep the basis of the science in hypertension or hyperlipidemia, but then we have to come together to give a message to the practicing doctor...they [the guidelines] have to interface, they have to intertwine."

Dr. Alice Jacobs: "It's hard to recommend something that's not really broken, and these programs have done so well; but there's some attraction to think about integration.... Even though our knowledge and expertise tends to be siloed, the patients really aren't...and the risk factors tend to cluster—for example, the metabolic syndrome."

Dr. Paul Whelton: "We have established guidelines. It's so fortuitous that those are in place. I think if we didn't have [them], it would be mayhem....Whatever we do in modification, we don't want to throw the baby out with the bath water."

Dr. Xavier Pi-Sunyer: "[In recent years] the disciplines [of different professional groups] have come together....I think it's really important to bring things together....The cardiologist gives a statin and an antihypertensive drug and thinks he's done it. The diabetologist gives an antidiabetes drug and thinks he's done it. And in fact, they haven't. They have to do a lot with regard to lifestyle, which they don't like to do and don't know how to do and which is part of the treatment for everybody....It's not going to be solved by just giving two drugs, or three drugs, or four drugs, but it's a holistic kind of approach....[NHLBI] should have an overarching guideline too."

Ms. Nancy Loving emphasized the patient's perspective and essentially felt that patients are confused. They see the release of so many guidelines as "random" chaos, get discouraged, and end up tuning it out and giving up.

Dr. McGinnis summed up by saying there were three guestions and answers:

- What's worked? The focus to date on the conditions.
- What's missed? The common elements (e.g., diet and physical activity) and the collective elements, multiple risks in given individuals.
- What's coming? The focus on personalized medicine. With the progress to be seen in genetic mapping over the next decade, it's clear that the focus will be much more on the specific individual.

Dr. Virend Somers emphasized that the current guidelines have been successful, that in fact some patients do read them, and that the guidelines enforce a standard of care compliance. He then suggested that NHLBI go one step further and have guidelines for CVD prevention.

Dr. Sidney Smith began his comments by saying "I would strongly recommend an integrative program." He went on to say that to treat patients, the individual guidelines are not sufficient; they lack an integrative function. In turn, he felt that this represented an opportunity to broadly partner with other organizations, but he also urged that the science brought to the table through the development of risk-factor guidelines not be abandoned.

Dr. Nabel then asked Dr. Smith how he would achieve this integration, provided that NHLBI keeps the science-based education programs as they are.

He responded that he wasn't sure whether to establish a broader group for integrating the risk factors for the physicians or to have, perhaps, a basic science statement that would come out and then a clinical statement with broad recommendations.

As the discussion concerning this topic concluded, everyone was—as Dr. Alan Hirsch phrased it—"a fervent supporter of science-based individual guidelines...and also simultaneously a fervent supporter of integration." Specific and cogent last comments included:

- Dr. Hirsch: Clinicians and patients are being overwhelmed and are fatigued and cannot possibly follow all the individual guidelines. Taking the car dashboard as a metaphor, it's hard for a physician to look at a cluttered dashboard with 12 gauges, one for each committee, and know how to drive the car. Integration is bringing groups together every 2 or 3 years to decide what the three most important gauges are for patients. At the same time, this partnering can help ensure that all these organizations' dashboards look essentially the same.
- Dr. Linda Van Horn: The evidence is outcome-specific, but lifestyle is integrated. The application of the science comes in the behaviors that need to be addressed. There is a prevention-oriented lifestyle that underlies every other recommendation we make.
- Dr. Stephen Corber: In terms of integration, we need to think about how the risk factors interact with each other and affect each other. The risk factors not only come together, but addressing one or some combination affects beyond what you think it's affecting. The guidelines are necessary but not sufficient.
- Dr. Gregory Burke: To move to the next step, we have to devote more resources [to improve public health] because the people we are not reaching now are harder to reach. In addition, integration offers economies of scale.

- Dr. Susan Bennett: The integration we are talking about is not so much an intellectual activity as it is a process or systems activity. Dr. Bennett gave, as an example, the paper-based tool used in her medical center that requires the physician to perform in an integrated way and helps the patient understand that everything is integrated.
- Dr. Stephen Daniels: There is a need to look at specific populations as well as at risk
  factors, especially in that the current guidelines contain gaps related to these populations
  and have not worked very well. Dr. Daniels went on to say that "prevention is best when it
  starts early" and that there was a need to think "developmentally" about this and focus
  especially on the pediatric age group. In this context he felt that pediatricians and family
  physicians could help address primary prevention.
- Related to the issue of special populations, Dr. Smith raised the point that the Institute of Medicine has called for more evidence-based practice and that the current guidelines are "vague" about the evidence in very important groups—in the elderly, in ethnic minorities, and in relation to gender differences that may exist.
- Dr. Philip Greenland suggested that an integrated approach is called for because three issues cut across the risk factors:
  - o The need to prevent the development of the risk factors themselves.
  - A required standardized assessment of cardiovascular risk that includes the risk factors but cuts across them all (he felt that the assessment of risk was currently different in the existing guidelines).
  - The imperative to increase physician adherence to the guidelines through a simplified and integrated guideline—"three or four pages," one person suggested—especially since "90 percent of patients have more than one risk factor." (Later in the discussion, Dr. Somers disagreed and said that many patients have only one risk factor—but this appeared to be a minority view.)
- An integrated guideline is also important for the community, according to Dr. Hirsch, to help
  us attain a "healthy cardiovascular culture" and not "fatigue" our community partners with
  multiple guidelines.
- Commonly expressed concerns were the relative lack of resources going toward prevention compared to treatment as well as the need for more emphasis on public health strategies.
   Dr. John Finnegan brought up Jeffery Rose's theorem and paradox: when trying to shift risk in the whole distribution and focus on those with moderate risk (instead of those with extreme risk), only modest individual change may be achieved, but the health ramifications for the population as a whole can be quite dramatic.

# Topic 2: Enhancing Dissemination of NHLBI-Funded Research

The Thought Leaders input on this topic was more disparate in nature and overlapped to some extent with the discussion of Topic 1.

Early in the discussion, Dr. George Mensah suggested that a means for enhancing dissemination of the research was for "a set of simplified guidelines on how to prevent heart disease" to come out jointly from the NHLBI, AHA, ACC, and CDC. He also addressed the need to begin looking at the audience and to have the guidelines broken down by the three levels: community, general physician, and the specialist.

This theme was seconded by Dr. Smith who stated that "the impact of a guideline is directly related to its *simplicity* and the *number of people* involved in partnering and distributing it." He also pointed out that the more guidelines there are "out there," the more possible confusion, and that "the more uniform the message in the country, the better." Dr. Smith thought that "an integrative process in which NHLBI has a major leadership role...would be very well received."

Dr. Finnegan, an investigator on the REACT study, had another perspective on how to enhance dissemination. He noted that the REACT effort was a model for effective dissemination and implementation of the science with NHLBI working closely with the grantee staff. A community effort was mounted collaboratively that focused upon activating the community, changing and influencing its systems, and working with health care providers and professionals. Then, on the translation side, NHLBI's Office of Prevention, Education, and Control took the findings and repackaged them as a set of technologies for broader dissemination to health care professionals and providers. Dr. Finnegan concluded by stressing the critical nature of the dissemination component: "If your goal is to improve public health in the United States, then at some point you have to make sure that those results and those techniques and those guidelines are disseminated out there in a useful form....We're sort of rearranging deck chairs on the Titanic if we keep doing great research but nothing is going out there to largely change or shift population health."

Similarly, Dr. Wilson Pace emphasized that dissemination goes far beyond distributing information. We are dealing with complex adaptive systems at all levels, and we need to deal with the science of how to effect sustainable change. He also commented on how the technology can help synthesize complex guidelines for the clinician. The crucial nature and difficulty of system changes had been mentioned previously by Drs. Schuster and Mark Carlson, among others, during the discussion.

One reaction to this statement was that outreach must focus not only on treatment but also on prevention. This focus was viewed as especially true for the lifestyle issues such as exercising and eating more fruits and vegetables. Dr. Pi-Sunyer noted that for a risk factor such as obesity, treatment is difficult for the average physician and that prevention, beginning with young children, was the more feasible approach.

Dr. Whelton began by saying that "this part [of the discussion] is the 800-pound gorilla because we all know we've got this big chasm [between research and utilization]. We all agonize over it." He went on to say that NHLBI has an important role to play in culture change and creating the knowledge of how to do it better. He added that leveraging others was key as NHLBI's primary role was research. Dr. Whelton also stressed the need for policy change, especially in relation to diet and physical activity, and mentioned the Agency for Healthcare Research and Quality (AHRQ) as another important partner. Finally, he stated that the dissemination efforts of the Antihypertensive and Lipid-Lowering Treatment to Prevent Heart Attack Trial (ALLHAT) should be examined.

The need for greater emphasis on prevention surfaced throughout the day's discussion and especially in relation to the young. Both Dr. Greenland and Dr. Pace saw a need to shift more resources into prevention. Dr. Hector Balcazar brought up the community as a key partner and stressed that it was critical to be sensitive to specific community issues and the uniqueness of each community in relation to prevention approaches as well as treatment. Dr. Somers stressed the need to get away from the "guideline paradigm" when disseminating information to the public, especially children, and focus more on behavior.

Later in the discussion, Dr. Somers suggested that partnering with schools, particularly innercity schools, was an important step in bringing about behavior change. Dr. Daniels added that "schools are not just a pathway to kids but they're a pathway to families." He noted too that in regard to the prevention of smoking, schools had been very helpful. They were not as successful in the area of physical activity, but nevertheless Dr. Daniels concluded by saying that schools are "not an easy target but I think they're an important one."

The concept of an NHLBI core laboratory was then proposed for consideration. Dr. Gregory Burke said that scientists feel that they are done once they have published in a professional journal, and they are amateurs at information dissemination, whether it be to the public or to their scientific colleagues. But, he conceded, "we really could do better," not only in relation to the major trials but also to the smaller ones: "There are pearls of science that come out across the board and may or may not get disseminated." Thus, the need for a core laboratory: "...I'm going to suggest, similar to what many of my laboratory-based colleagues believe, core labs and core resources." Expanding on this idea, Dr. Burke said that one of the creative strategies that could come out of the Thought Leaders Discussion would be for NHLBI to "develop a core laboratory whose job it is to help those scientists...move and translate findings into a new area, and not just focus on the big science but also focus on thinking about the aggregate picture and reinforcing the themes that are out there before that study was published."

Two comments relating to behavior-change research concluded the discussion around this topic area. Dr. Stephen Corber suggested, as a few other participants had previously, that behavior change was a good area for NHLBI to do research—research about how physicians behave and how people change.

Dr. Finnegan took issue with this suggestion and emphatically stated that "this Institute [NHLBI] has been funding studies looking at behavior for almost 40 years...so the idea that we know nothing about behavior, or very little about behavior, or very little about how to effect change is *simply not* the case...the research is there. What *is* the case is...how do you make that connection between the research we fund and the dissemination process to get it out there to have a major league effect on population health?"

# Topic 3: Putting Research Into Action Through Broadened Stakeholder Collaboration and Knowledge Exchange

Dr. Moser stated that one of the best ways to leverage information and get it out to the public and physicians was through the pharmaceutical industry. He felt strongly that NHLBI had to work with industry. He pointed out that pharmaceutical companies had disseminated "hundreds of thousands" of publications for the NHBPEP in "an unbiased way." Mr. Miguel Trevino, Jr. also felt that there were constructive ways of collaborating with these companies. In addition, Dr. Moser mentioned the AARP as an important organization that should be leveraged better to help disseminate the science.

Most other participants seemed wary of working with the pharmaceutical industry. Dr. Greenland said that industry was "not necessarily our friend" and that it was a "slippery slope" to partner with industry. In fact, he saw industry as representing powerful competition in getting objective, science-based health messages disseminated, especially because "industry is in the physician's office every day."

However, Dr. Van Horn thought that guidelines—if designed and disseminated carefully—could effectively drive industry to promote positive health outcomes. This was in spite of the negative experience of nutritionists with industry in relation to the low-fat diet. She also mentioned the benefits of working with advertisers, especially as a source of marketing expertise.

Dr. Schuster stated the need for NHLBI to take an approach employed by major corporations and set a challenging goal for itself, a "Big Hairy Audacious Goal" (BHAG). As an example, he suggested the goal be to have 90 percent of the population under control for the risk factors within 10 years.

**Collaboration Among Stakeholders as a Solution.** The last few speakers, in attempting to answer the question of *how* NHLBI could move the bar and achieve significant improvement in heart health and CVD reduction, all stressed the need for broad collaboration and partnering. They said that NHLBI and the various clinical and public health stakeholders would never be able to outspend industry, but that enough groups coming together and speaking with one voice would have the impact, the critical mass, required to change the culture.

Dr. Burke noted that "all kinds of people have the same goals as we do...to make the country healthier." He believes that NHLBI has the stature and credibility to take the lead in this collaborative process, and these strengths could be used to work with partners strategically at many levels.

During the discussion, a number of key partners or stakeholders were mentioned:

- The research community
- AHA
- ACC
- ADA
- CDC
- AHRQ
- · Patient advocacy groups
- Other relevant NIH institutes

Dr. Mensah, in looking at strategic partners in relation to a reduction in health disparities in the United States, suggested three other key partners:

- HRSA and its community health centers
- State departments of health
- CMS

Dr. Mensah pointed to CMS as an especially important partner in reaching the elderly, as CMS is now paying for preventive screening for those who have turned 65. Dr. Smith added that CMS is talking about paying for quality. If NHLBI could work collaboratively with them, it could have a major impact on health systems and thus provider behavior and adherence to the guidelines. Conversely, if "we put out guidelines about cholesterol and hypertension, and physicians aren't being paid for screening cholesterol or looking at hypertension in the elderly, you've got a disconnect of major proportions."

The last speaker, Dr. McGinnis, made five recommendations—"in the blue sky mode"—for the NHLBI:

1. Develop an internal working group to identify five or six key areas of behavioral research

- that have conclusive findings but have not been applied, and quantify the human and economic gains that could be achieved by applying what is known.
- 2. Establish a working group that includes the NHLBI as well as multiple organizational stakeholders to develop a proposal on integrative approaches to patients with multiple risk factors.
- 3. Develop an NIH-wide initiative that includes a series of large-scale studies and community-based interventions on nutrition and physical activity.
- 4. Develop a collaborative effort across NIH and with CMS and AHRQ to develop and test clinical system instruments, assessment protocols, record prompts, and tools to help implement clinical guidelines.
- 5. Sponsor an NIH-wide assessment on how to integrate lifestyle issues into the inevitable emergence of personalized medicine as an approach to clinical care.

## Conclusion

The co-chairs, Dr. Jones and Dr. Nabel, both thanked the attendees for their participation in what they saw as a fruitful and enlightening discussion. Dr. Nabel went on to say that she viewed the Thought Leaders Meeting "as the first of many conversations we will have collectively or individually around various topics." She then reflected on the afternoon's discussion. She said that the participants had clearly communicated the importance of the NHLBI's national programs and the science-based and evidence-driven guidelines. At the same time, participants had expressed a need for some type of integration to address overlapping risk factors and to simplify the messages and tools.

On the topic of dissemination, Dr. Nabel saw partnerships as the wave of the future and that all the groups had to work together. Through the leveraging of resources, through partnerships, the NHLBI's dissemination and education component could achieve its greatest effectiveness.

Dr. Nabel said the NHLBI has many opportunities to expand the knowledge base, including research in behavior change as well as how to promote the implementation of what had been already learned in this area. She also agreed with the need to bridge the gap between research and utilization and to think of different ways of doing business. She noted the opportunity now to engage in strategic planning and working with a variety of partners—CMS, CDC, and professional organizations, as well as organizations with whom NHLBI has not traditionally collaborated.

In closing, Dr. Nabel said that the meeting had "energized and encouraged" her, and she wanted to optimize what the Institute was doing in its OPEC program to make the most of the NHLBI's research investment and findings.

# **Appendix A**

National Heart, Lung, and Blood Institute

# Cardiovascular Disease (CVD) Thought Leaders Meeting

Research Translation, Dissemination, and Application: Moving Toward a New Vision and Strategic Framework

Wilson Hall, Building 1 National Institutes of Health Bethesda, Maryland 20892

> June 17, 2005 12:30 p.m.-4:00 p.m.

#### **AGENDA**

Guided by its mission and mandate to translate and disseminate research findings, the NHLBI CVD Thought Leaders Meeting is being convened as a starting point for creating a strategic plan and framework for enhancing research translation and dissemination.

12:30 p.m.	Registration and Light Refreshments	
1:00 p.m.	Welcome and Introductions	
1:15 p.m.	Creating a Vision for the Future: Opportunities and Challenges	Elizabeth G. Nabel, M.D. Co-chair
1:35 p.m.	Agenda Review	Daniel W. Jones, M.D.

## Focused Discussions

1:45 p.m. Topic 1

Research Translation and Dissemination: NHLBI's National Education Program Models for CVD Risk Factor Prevention and Control; Early Warning Signs and Symptoms of Acute Coronary Syndromes; and Community Outreach to Meet the Needs of the Underserved

Co-chair

#### **Key Questions**

 NHLBI has been active in developing clinical guidelines for detection and management of CVD risk factors as integral elements of, and programmatic platforms for, the CVD risk factor education programs—National High Blood Pressure Education Program, National Cholesterol Education Program, NHLBI Obesity Education Initiative.

What are the differences between development of clinical guidelines by NHLBI and by professional societies? Do these differences militate for or against continued NHLBI involvement in guidelines development, e.g., with respect to scientific objectivity of the guidelines and adequacy of the process for scientific review; minimizing influence of special interest groups; imbedding of guidelines development in a national education program committed to promoting adoption and implementation of recommendations vs. stand-alone development; and encouraging appropriate involvement of stakeholders?

- 2. What are the bases for determining when a clinical guideline should be integrative (e.g., dealing with multiple risk factors) and when it should be focused (e.g., single risk factor)? For example, if scientific developments with respect to one risk factor necessitate updating of the guideline for that risk factor, when is it desirable to produce an integrative update and when a focused update? What approaches would enable integrative guidelines to provide adequate guidance on clinical management of individual risk factors?
- 3. Given their role in guiding clinical practice and in conducting public education campaigns, should consideration be given to the integration of the risk factor education programs into an overarching CVD education program? Or, should the education programs maintain their unique visibility?

Should the NHLBI consider merging the existing education programs/ initiatives into a single national education program? Or, should the existing programs maintain their unique identity? If the latter, how should the common interest in nonpharmacologic or lifestyle behavior strategies to prevent CVD and its risk factors be addressed?

Interactive Discussion

Recommendations

2:30 p.m. Topic 2

Enhancing the Return on the Broader CVD Research Investment: Disseminating the Results and Promoting the Use of NHLBI-Funded Research

#### **Key Questions**

- 1. There is a tremendous lag time of 15–20 years between the initial release of research findings and their widespread utilization to improve the public's health. Whose job is it to disseminate CVD research evidence? What should be the roles for the development of useful and useable dissemination products targeting professionals, patients, and the public for:
  - NHLBI as funder?
  - Grantees?
  - Other Federal agencies?
  - Professional societies and voluntary health organizations?
  - Patient advocacy groups?
  - The media?
- 2. In an effort to respond to the need to expedite the dissemination of research findings, NHLBI developed a Policy on Planning for Dissemination of Research Results in RFAs and RFPs and for Investigator-Initiated Studies >\$500,000 that went into effect December 2002 (see Background section for dissemination requirements). What are your thoughts about this requirement? Does it need to be revised?
- 3. The new NHLBI dissemination requirement will increase the amount of information and types of findings that need to be disseminated to various audiences. The development of a more effective NHLBI infrastructure may be required to assess the emerging evidence base from NHLBI-funded research in context with the existing collective body of evidence and to organize it into a focused "Priority Conditions" strategic dissemination plan. The plan will need to be responsive to the overarching goals of Healthy People 2010 to increase quality and years of healthy life and eliminate health disparities. What should the NHLBI consider in the planning process? What role should stakeholders play in the planning process?
- 4. What are possible new areas of emphasis for NHLBI relative to better identifying promising or best practices and improving dissemination and utilization of research results?

Interactive Discussion

Recommendations

#### 3:15 p.m. Topic 3

Putting Research Into Action Through Participatory Linkages With Multiple Stakeholders: Models for Knowledge Exchange, Collaborative Dissemination Strategy Planning, and Knowledge Brokering

#### **Key Questions**

 Achieving successful dissemination of research evidence is more probable when appropriate input from intended users is obtained. "Siloed" worlds of researchers, practitioners, policy decisionmakers, and patients contribute to lack of opportunities for organized exchange of information to ensure relevance of research and application tools and approaches sensitive to the needs of intended users.

How can we bridge the gap between the research community involved in the generation of research evidence and the use of that knowledge base by relevant target audiences? What are some of the untapped ways in which stakeholder organizations, the NHLBI, and its grantees can work together to enhance dissemination and utilization of these research findings?

2. What kinds of stakeholder venues and collaborative partnerships (national and international) should NHLBI consider sponsoring in the future to deal with this issue? How can research needs identified by clinical or public health practitioners, patients, and the general public be best communicated to successfully inform future research?

Interactive Discussion

Recommendations

3:45 p.m. Summary and Next Steps

Dr. Nabel and Dr. Jones

4:00 p.m. Adjournment

# **Appendix B**

# National Heart, Lung, and Blood Institute Cardiovascular Disease Thought Leaders Meeting

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June 17, 2005

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## **Appendix C**

#### DISCUSSION TOPICS BACKGROUND

#### NHLBI CARDIOVASCULAR DISEASE THOUGHT LEADERS MEETING

June 17, 2005

#### Topic 1

In September 1972, the National Heart, Blood Vessel, Lung, and Blood Act of 1972 (Public Law 92-433) provided broad legislative authority for the National Heart and Lung Institute (NHLBI) to conduct a program to provide the public and health professionals with health information. The Health Research Extension Act of 1985 (Public Law 99-158) specifically directed the NHLBI Director to collect, identify, analyze, and disseminate . . . to patients, families of patients, physicians and other health professionals, and the general public, information on research, prevention, diagnosis, and treatment of heart, blood vessel, lung, and blood diseases, [and] the maintenance of health to reduce the incidence of such diseases.

In response to the legislative mandates, the NHLBI's Office of Prevention, Education, and Control (OPEC) coordinates the translation and dissemination of research findings and scientific consensus to health professionals, patients, and the public, so that information can be adapted for and integrated into health care practice and individual health behavior. The NHLBI health education programs and initiatives established through the OPEC address high blood pressure, high blood cholesterol, asthma, early warning signs of heart attack, obesity, sleep disorders, women's heart health, peripheral arterial disease (PAD), and chronic obstructive pulmonary disease (COPD). For reducing high blood pressure, high blood cholesterol, and obesity, two approaches are used: one focuses on individuals at high risk, and the other focuses on the general public. Special attention within the Institute's mandate is given to minority populations that are disproportionately affected by disorders. The four largest education programs have coordinating committees representing national medical, public health, and voluntary organizations as well as other Federal agencies. The committees help to plan, implement, and evaluate the Institute's professional, patient, and public education programs. The following briefly summarizes the education programs and initiatives related to cardiovascular disease (CVD):

The National High Blood Pressure Education Program (NHBPEP) was initiated in 1972 to reduce death and disability related to high blood pressure. NHBPEP employs a comprehensive strategy to mobilize, educate, and coordinate groups concerned with hypertension prevention and control.

The National Cholesterol Education Program (NCEP) was initiated in 1985 to educate health professionals and the public about high blood cholesterol as a risk factor for coronary heart disease (CHD) and about the benefits of lowering cholesterol levels to reduce illness and deaths from CHD. Its goal is to reduce the prevalence of elevated blood cholesterol in the United States and, thereby, contribute to reducing CHD morbidity and mortality.

The National Heart Attack Alert Program (NHAAP) was initiated in June 1991 to reduce morbidity and mortality from heart attack, including out-of-hospital cardiac arrest, through

education of health care providers (e.g., physicians, nurses, and emergency medical services personnel), patients, and the public about the importance of rapid identification and treatment of individuals with heart attack symptoms. In 1997, the Program's scope was broadened to include early identification and treatment of individuals with unstable angina.

The NHLBI Obesity Education Initiative (OEI) was launched in January 1991 to inform the public and health professionals about the health risks associated with overweight and obesity. Obesity is not only an independent risk factor for CVD, but also is a contributor to high blood pressure and high blood cholesterol and is related to sleep apnea. The OEI employs a comprehensive strategy to mobilize, educate, and coordinate groups interested in preventing and treating overweight and obesity.

The NHLBI Women's Heart Health Education Initiative was begun in 2001 to coordinate research and educational programs related to CVD in women. In 2002, it started The Heart Truth campaign to raise awareness of heart disease among women, 40 to 60 years old. A creative element of the campaign is The Red Dress Project, which uses the red dress as a symbol for women and heart disease awareness.

In 2004, the NHLBI directed its attention to raising public awareness about PAD. Together with the newly formed PAD Coalition, it has initiated planning for a 3-year campaign to raise public awareness. The NHLBI also is continuing its collaboration with the Vascular Disease Foundation and other interested organizations to identify short- and long-term goals associated with raising awareness of PAD, educating health care providers and others about PAD, and addressing other vascular diseases.

As a key part of its response to the Healthy People 2010 Objectives for the Nation, the NHLBI initiated a new funding mechanism in 2001 to establish CVD educational outreach programs in high-risk communities. The program—Enhanced Dissemination and Utilization Centers (EDUCs)—is a partnership between the NHLBI and local communities to eliminate cardiovascular health disparities and improve the health of underserved populations. Since its inception, two sets of six EDUCs have been awarded. These centers served more than 30 communities in 10 States.

The Institute's "Salud para su Corazón" (Health for Your Heart) Initiative, a community-based heart health program for Latinos, has expanded across the United States to include communities along the Texas/Mexico border and along the southern border areas of California and New Mexico. Trained local lay health workers (promotores) apply the values and culture of the communities and mobilize partners to teach people how to reduce their risk of developing CVD. As advocates for change, they have increased the number of Latinos in their communities who are engaging in heart healthy behaviors.

The NHLBI and the Indian Health Service (IHS) have worked together since 2000 to bring heart health to American Indian and Alaska Native (AI/AN) communities. Initial steps were focused on identifying the unique needs and issues that affect tribal communities. The NHLBI developed a training manual, *Honoring the Gift of Heart Health*, for community instructors to enable them to provide a culturally appropriate 10-session course on heart health. In 2003, a national training workshop was held for key tribal leaders and health practitioners in AI/AN communities across the United States. As a result, trainers will be available to conduct future training sessions.

The NHLBI's Asian American and Pacific Islander (AAPI) Cardiovascular Health Outreach effort focuses on four underserved groups who have high levels of CVD risk factors, such as high

blood pressure, obesity, and physical inactivity. Individuals of Filipino, Vietnamese, Cambodian, and Native Hawaiian heritage comprise the targeted audience. To date, cardiovascular health educational materials have been developed for those of Filipino and Vietnamese heritage. A school-based intergenerational cardiovascular health education curriculum to be used to educate Native Hawaiian elementary school children is under way.

Through its international programs, the NHLBI contributes to and benefits from the rapidly developing global knowledge base in medicine, science, and technology related to its mission. The Director and senior NHLBI staff serve as consultants to and partners with the Pan American Health Organization (PAHO) and the World Health Organization (WHO). The Institute's international activities are conducted through multiple mechanisms, including government-to-government and institute-to-institute agreements; joint research projects; joint symposia and workshops; and joint documents, publications, grants, contracts, and fellowships.

The NHLBI contributes to worldwide health plans by working through international organizations in areas within its mandate. In recognition of its leadership and contributions to global and international health, the NHLBI was redesignated as a WHO Collaborating Center for Research and Training in 2004. At the regional level, the NHLBI is addressing the pandemic of CVD in North, Central, and South America and the Caribbean through support of the Pan American Hypertension Initiative (PAHI), a public/private partnership initiated by the NHLBI and the PAHO in collaboration with seven international scientific organizations: the World Heart Federation, the Inter-American Heart Foundation, the Inter-American Society of Cardiology, the Inter-American Society of Hypertension, the Pan American Network of CARMEN Programs, the Latin American Society of Nephrology and Hypertension, and the World Hypertension League (WHL). The initiative seeks to reduce morbidity and mortality from CVD by controlling hypertension, a major risk factor for the disease, in an estimated 160 million people who already have the condition and by preventing it in millions more at risk because of their unhealthy lifestyles. In 2003, the Institute and PAHO began a 5-year collaboration in CVD prevention and control based on PAHI and the Institute's "Salud para su Corazón" Initiative.

# Topic 2: Policy on Dissemination Plans in RFAs and RFPs, and Investigator-Initiated Applications With Direct Costs >\$500,000

Example from the current RFA titled, Pediatric Heart Network (applications are due September 23, 2005):

6. Other Submission Requirements

**Dissemination Section:** Applicants must include in their application/proposal a plan for dissemination of research results, and such a plan should include:

- Identification and description of target audience of the dissemination plan.
- Description of the methods to be used to reach the audience.
- Appropriate benchmarks for success.
- Appropriate additional personnel for developing and implementing the dissemination activities.
- An appropriate budget for the proposed dissemination activities for the last year of requested funding.

• A statement that the investigators agree to discuss and finalize the dissemination plan with Institute staff prior to its implementation.

Clinical center applicants must include a statement of willingness to work collaboratively with the other funded sites to prepare a joint dissemination plan after award. The DCC application/proposal should describe methods to coordinate the dissemination planning and implementation. The DCC must include a budget and justification for any additional costs of this collaborative effort.

When study results are available, the Principal Investigators (and if appropriate, other personnel from their project) and Program and NHLBI Office of Prevention, Education, and Control (OPEC) staff will meet (e.g., face-to-face, teleconference) to:

- Identify the key message(s) to deliver and key audiences.
- Discuss the results of the research.
- Determine the appropriateness of implementing the original dissemination plan(s).
- Reach agreement on a final dissemination plan for the research results and, if relevant, any intervention materials.