Summary Minutes

In July 2006, the National Cancer Institute’s (NCI) Center to Reduce Cancer Health Disparities (CRCHD) and the National Center on Minority Health and Health Disparities (NCMHD) partnered for the first time to host the annual Cancer Health Disparities Summit. The event brought together participants from the Community Networks Program (CNP); the Patient Navigation Research Program (PNRP); the Minority Institution/Cancer Center Partnership Program (MI/CCP); the Centers for Population Health and Health Disparities; the Cancer Disparities Research Partnership (CDRP) Program; and the Centers of Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training (Project EXPORT).

The theme of the 2006 Summit, *Strengthening Our Culture of Collaborations for Reducing Cancer Health Disparities*, recognized the current climate of fiscal constraint and the pressing need to maximize existing resources by enhancing collaborations. The objectives of the Summit were to:

- Examine issues of common need.
- Share strategies, models, and tools for providing solutions within respective programs and communities.
- Empower partnerships with access to resources needed to sustain programs that benefit the community.
- Facilitate networking and discussion on unique issues that influence programmatic progress.

Representatives from NCI and NCMHD provided Summit participants with an overview of current efforts to address cancer health disparities. Individuals from communities experiencing health disparities shared their perspectives and invited panelists imparted information on funding opportunities, emerging technologies, and the influence of health disparities research on health policy. Grantees from a number of NCI and NCMHD programs also presented during plenary and poster sessions, providing project overviews as well as insight into best practices. Through a series of breakout sessions, participants discussed ways to promote and sustain cancer health disparities programs and formulated recommendations to NCI and NCMHD regarding how these agencies can best support the cancer health disparities research community.

**July 17, 2006**

**Call to Order**

*Tarsha McCrae, M.P.H., Public Health Analyst, CRCHD, NCI*

Ms. McCrae welcomed the participants to the 2006 Cancer Health Disparities Summit and informed them that the meeting marked the first time that NCI and NCMHD had come together to recognize the work of their grantees and encourage the cancer health disparities research community to strengthen its culture of...
collaboration to reduce cancer health disparities across the Nation. She explained meeting attendees would participate in interactive plenary sessions, networking sessions, and working breakout groups throughout the course of the 2.5-day event. Ms. McCrae also asked participants to complete and hand in the evaluation forms in the program notebook at the end of each day of the meeting. She directed participants to refer to the program notebook for detailed biosketches for all of the moderators and panelists on the meeting agenda.

Welcoming Remarks
Sanya Springfield, Ph.D., Acting Director, CRCHD, NCI

Dr. Springfield reiterated the fact that the 2006 Summit was a landmark event that brought together representatives from some of the most exciting, effective, and promising programs addressing cancer health disparities across the country. She also provided an overview of the meeting agenda. The meeting would begin with presentations from National Institutes of Health (NIH) and NCI leadership who would describe the commitment of their Divisions, Centers, and Offices to reducing cancer health disparities. This would be followed by updates from the various programs participating in the Summit. Dr. Springfield asked representatives from these programs to stand; she and the other meeting participants applauded the past accomplishments of these programs as well as their current and future efforts in the area of cancer health disparities.

The second day of the meeting would profile the best practices of cancer health disparities programs and engage meeting participants in discussions of areas that require special attention during times of budgetary constraint, including effective ways of managing, leveraging, and sharing resources. Participants would also hear about emerging technologies being developed by NCI that could potentially help address disparities if harnessed in an effective and timely manner. Dr. Springfield encouraged participants to attend the evening poster sessions in order to network with other researchers in the field.

Dr. Springfield challenged meeting participants to view the 2006 Summit as the beginning of a new process that would enable them to develop a road map for the future of their programs and influence the direction of the commitment of NCI, NIH, and the Department of Health and Human Services (DHHS) to cancer health disparities.

John Ruffin, Ph.D., Director, NCMHD

Dr. Ruffin welcomed the participants to the meeting on behalf of NCMHD and congratulated them on their commitment to the issue of health disparities. He thanked Dr. Springfield and NCI for inviting NCMHD to co-host the Summit. He also thanked Dr. Derrick Tabor, Director of NCMHD’s Project EXPORT, for his work in planning the Summit. Finally, he thanked the grantees for increasing the understanding of how diseases like cancer affect different populations.

Dr. Ruffin informed the group that NIH would be convening several additional meetings addressing health disparities in the coming months and years. In 2007, NCMHD, in collaboration with other NIH Institutes and Centers, will launch the first of three forums on health disparities research to showcase progress that has been made across NIH to date. The Office of Behavioral and Social Sciences Research will also be convening a health disparities conference in October 2006. These meetings, along with the Summit, will help shape the health disparities research agenda, increase understanding of the problem, and eliminate the burden of cancer in underserved communities.

Dr. Ruffin encouraged meeting participants to think about the essential concepts of partnership and sustainability over the 3 days of the Summit. He challenged them to use the conference as an opportunity to build on existing partnerships and establish new ones in order to sustain work in the area of health disparities. He emphasized the need to build unique partnerships to bridge existing gaps, including gaps in
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Dr. Clanton welcomed the participants and related his regret for being unable to attend the Summit due to a conflicting meeting with one of NCI’s global partners. He voiced his belief that the Summit would provide a great opportunity to review progress made and look ahead to future progress in the area of cancer health disparities. He informed the group that reducing cancer health disparities is one of the main areas of emphasis in the NCI goal to eliminate the suffering and death due to cancer.

In this regard, Dr. Clanton reported that the NCI recently held its first Institute-wide workshop on enhancing interactions to reduce cancer health disparities; more than 250 people from throughout NCI convened to assess efforts and propose strategies for enhancing collaborations across NCI to address cancer health disparities. He also announced the recent formation of a Health Disparities Integration/Implementation (I²) Team, which will help identify possibilities and solutions in a time of decreased budget. Finally, he reported that implementation of the recent Trans-HHS Cancer Health Disparities Progress Review Group recommendations is forging alliances across the Department of Health and Human Services.

Dr. Clanton congratulated Dr. Springfield on doing a terrific job as Acting Director of CRCHD while maintaining her position as Director of the NCI Comprehensive Minority Biomedical Branch. He informed meeting participants that the process of naming a permanent Director of CRCHD is under way.

Dr. Clanton closed by thanking attendees for their work on behalf of underserved communities and for their participation in the Summit.

NIH/NCI Funding Community: Our Investment in Disparities Research (Part I)

Moderator: Michaele Christian, M.D., Division of Cancer Treatment and Diagnosis, NCI

Dr. Christian introduced herself as Director of the Cancer Therapy Evaluation Program, the extramural cancer treatment clinical trials program at NCI. She informed meeting participants that this session would provide NCI staff as well as extramural grantees the opportunity to learn more about the activities of each of the NCI and NCMHD programs and components and prompt people to think about creative ways to leverage resources to make a larger impact on cancer health disparities.

Investments in Eliminating Health Disparities: Overview of Select NCMHD Programs

Derrick C. Tabor, Ph.D., Program Official, NCMHD

Dr. Tabor presented in place of Dr. Reuben Warren, who was unable to attend the Summit.

The programs sponsored by NCMHD strive to eliminate health disparities and improve minority health, which are central goals of Healthy People 2010. The NCMHD has also been actively engaged in the development of the NIH Health Disparities Strategic Plan, which involves coordination of the health disparities activities of all of the NIH Institutes and Centers. The Institute of Medicine (IOM) conducted
an evaluation of the Plan and published their findings in *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business*.

In 2003, the NCMHD had 24 full-time employees (not including contractors) and a budget of $185 million. After 2 years of increases, the NCMHD budget peaked at $196 million. The total budgetary authority of NCMHD in 2006 was approximately $195 million, with $182 million directly funding research on minority health and health disparities. The requested budget for 2007 is slightly lower—approximately $194 million with just under $180 million devoted to research activities. The NCMHD currently has 31 full-time employees.

NCMHD offers a number of funding opportunities. It supports basic, clinical, and behavioral research on health disparities populations or minority health conditions, including research on the causes of health disparities and methods to prevent, diagnose, and address health disparities. Research programs include the Centers of Excellence Program, the Community-Based Participatory Research Program, the Small Business Innovation Research (SBIR) award program, and the Small Business Technology Transfer (SBTT) award program. The SBIR and SBTT programs are widely underutilized. The NCMHD is currently sponsoring a Request for Applications (RFA) in partnership with the National Center on Complimentary and Alternative Medicines for projects examining complimentary and alternative approaches to health disparities.

NCMHD also supports training activities. In addition to the NCMHD Loan Repayment Program, we sponsor the Pathway to Independence Award Program, which helps postdoctoral fellows transition to teaching and faculty positions. The Minority Health and Health Disparities International Research Training Program provides opportunities for students and faculty to travel overseas and establish partnerships with international colleagues. NCMHD also supports the Initiative for Maximizing Student Diversity in partnership with the National Institute for General Medical Sciences. Currently, NCMHD does not offer research supplements for minority researchers.

NCMHD is involved in two research capacity-building programs: the Research Endowment Program and the Research Infrastructure in Minority Institutions Program. The NCMHD also devotes a portion of its budget to the NIH Research Conference Grant Program.

NCMHD will continue its work in these areas and hopes to explore partnership opportunities to accomplish even more.

**Division of Cancer Biology**

*Dinah Singer, Ph.D., Director, Division of Cancer Biology, NCI*

The Division of Cancer Biology (DCB) is responsible for supporting investigator-initiated basic research on the biology of cancer across the initiation-progression-metastasis continuum. The Division manages nearly 3,000 research grants with a total budget of almost $900 million. The Division interacts extensively with its grantees, providing scientific guidance and helping to establish new collaborations when appropriate. Particular attention is paid to new investigators, minority investigators, and investigators at minority-serving institutions (MSIs) to help them achieve their scientific and professional goals. In this regard, DCB sponsors an annual New Investigators Workshop to introduce these researchers to program staff and inform them about available resources. The Division can provide supplements to support unanticipated needs and new research opportunities, and works to develop and support initiatives in emerging areas of cancer biology.

Research on cancers that disproportionately affect racial and ethnic minority populations (e.g., breast, colon, lung, prostate, stomach, liver, and cervical cancers) is funded by nearly 900 DCB grants for a total of approximately $200 million; this accounts for nearly one-quarter of the DCB budget. NCI researchers investigate the molecular and cellular basis of these diseases and attempt to identify factors that give rise
to differing burdens of cancer. For example, research is under way to determine the molecular differences that account for the fact that breast cancer in African American women occurs earlier and tends to be estrogen receptor-negative and much more aggressive than tumors that occur in other populations. Researchers are also studying the transition of hormone-dependent prostate and breast cancers from hormone-dependence to hormone-independence, a change that is often accompanied by the development of resistance to therapy. Investigators have also developed animal models of human cancer that will help identify potential therapeutic targets and factors that contribute to invasion and metastasis. Liver cancer is another area of active research for DCB grantees; investigators are studying chemical, viral, and bacterial factors that cause liver cancer, as well as differences in susceptibility to these factors. It is hoped that this research will contribute to the development of prevention strategies and/or improved treatment approaches.

DCB does not support a formal training program; however, it does participate in the Minority Training Supplement Program and actively encourages its grantees to apply for these funds. Over the past few years the Division has awarded nearly 200 of these supplements.

Although DCB does not directly perform health disparities research, it demonstrates a commitment to understanding the underlying molecular and cellular basis of disease to ensure that the health needs of all people and populations can be addressed.

**Cancer Disparities Research, Resources, and Initiatives: 2006 Update**

*Robert Croyle, Ph.D., Director, Division of Cancer Control and Population Sciences, NCI*

The Division of Cancer Control and Population Sciences (DCCPS) has the largest health disparities research portfolio at the NCI. DCCPS activities related to health disparities are included in the Office of Cancer Survivorship; the Surveillance Research Program, which houses the Surveillance, Epidemiology, and End Results (SEER) program; the Behavioral Research Program; the Epidemiology and Genetics Research Program; and the Applied Research Program. In the last few years, the most rapidly growing area funded by DCCPS has been health services research. A recently released program announcement is addressing prejudice and discrimination in health care delivery research.

A number of data sets and updates have been recently released and are available for use by the general public, including meeting participants and their trainees.

- National Health Interview Survey Cancer Control Supplement 2005 data were recently released to the public and are available through both the DCCPS [http://appliedresearch.cancer.gov/surveys/nhis/](http://appliedresearch.cancer.gov/surveys/nhis/) and Centers for Disease Control and Prevention (CDC) Web sites.

- The Tobacco Use Supplement of the U.S. Census survey provides state-level data and has a very large sample size; many have used these data for health disparities research. These data can be found at [http://riskfactor.cancer.gov/studies/tus-cps/](http://riskfactor.cancer.gov/studies/tus-cps/).

- SEER-Medicare Database linked 2003 data have recently been made available. This large database allows for data analysis based on gender, race, age, geographic location, and other factors. These data can be found at [http://healthservices.cancer.gov/seermedicare](http://healthservices.cancer.gov/seermedicare). DCCPS is sponsoring a workshop on September 19th at the University of Minnesota for those interested in learning to use this database.

- The Health Information National Trends Survey (HINTS) collects data about the American public’s beliefs about cancer and their use of cancer-related information. This publicly accessible data set is available at [http://cancercontrol.cancer.gov/hints/](http://cancercontrol.cancer.gov/hints/); 2005 data were recently posted. Examples of ways these data have been used can be viewed in a recent special issue of *The Journal of Health Communications*. 
The Cancer Control Planet portal (http://cancercontrolplanet.cancer.gov) is constantly being updated. This site provides information about evidence-based products and access to related products. It can also help identify potential program and research partners in a certain state or community.

Cancer health disparities are being addressed by a number of DCCPS initiatives and programs.

- The Tobacco Research Network on Disparities (TReND; http://www.tobaccocontrol.cancer.gov), led by Pebbles Fagan at NCI and Richard Clayton at the University of Kentucky, addresses methodological and measurement issues surrounding data synthesis. The Network recently held a workshop examining the degree to which tobacco policy interventions have differential, and sometimes negative, effects on individuals with low income or women.

- The Transdisciplinary Tobacco Use Research Centers (TTURCs; http://www.cancercontrol.cancer.gov/ttuc/index.html) have numerous projects that focus on sociocultural aspects of tobacco use, often in conjunction with biological factors; for example, the University of Southern California TTURC is performing a cross-cultural comparison of Chinese in China and the United States regarding how the gene-environment interaction plays out within a cultural context.

- Some of the Centers of Excellence in Cancer Communications Research (CECCR; http://cancercontrol.cancer.gov/hcirb/ceccr/) focus on cultural tailoring of health communications messages.

- The Multiethnic/Minority Cohort Study (http://epi.grants.cancer.gov/ResPort/Multiethnic.html) is an example of a large cohort study in epidemiology that is relevant to health disparities.

- Centers for Population Health and Health Disparities (http://dccps.nci.nih.gov/populationhealthcenters/cphhd/) focus on scientific integration across multiple levels of analysis, including social, behavioral, and biological.

DCCPS engages in collaborations with other Government agencies to address health disparities. The NCI/CDC/Health Resources and Services Administration (HRSA) Cancer Collaborative works to improve cancer screening, referral, and follow-up. The CDC/NCI Cancer Prevention and Control Research Network funds CDC Prevention Research Centers to test methods to disseminate research findings into practice.

Data are currently being generated by the Southern Community Cohort Study (http://www.southerncommunitystudy.org), which is examining, among other things, cancer etiology in African Americans. The Cancer Care Outcomes Research and Surveillance Consortium (CanCORS; http://healthservices.cancer.gov/cancors/) is a prospective study of lung and colorectal cancer patients from diverse populations that will examine disparities in cancer care and factors that contribute to disparities in outcomes.

Research Activities in the Division of Cancer Epidemiology and Genetics

Robert Hoover, M.D., Division of Cancer Epidemiology and Genetics, NCI

Dr. Hoover presented on behalf of Dr. Joseph Fraumeni, who was unable to attend the Summit.

The Division of Cancer Epidemiology and Genetics (DCEG) performs population-based and interdisciplinary research to identify lifestyle, environmental, and genetic determinants of cancer risk and inform strategies for cancer prevention. Cancer health disparities prompt epidemiological studies into the causal factors and mechanisms of differences in disease burden between different populations. Factors such as gender, race, ethnicity, socioeconomic status, geography, urban-rural patterns, migration history, and time trends are major components of epidemiological research.
An analysis of esophageal cancer reveals that the incidence rate of squamous cell carcinoma of the esophagus is approximately five times higher in blacks than in whites, while the rate of adenocarcinoma of the esophagus is substantially higher in whites than in blacks. Over the past 15 to 20 years, rates of squamous cell disease have declined slightly, while there has been a dramatic rise in esophageal adenocarcinoma in whites over the same time period. This increase has been linked to the increasing rate of obesity in the United States, which causes gastroesophageal reflux disease and increased incidence of Barrett’s esophagus, a premalignant lesion. The excess incidence of esophageal squamous cell carcinoma among African American men has been correlated with alcohol use, tobacco use, diet, and low income. Socioeconomic status appears to be an important contributor to disease even when alcohol and tobacco use are controlled for.

Surveillance data have shown that the highest incidence of cervical cancer among black women is in rural areas of the Southeast and in the Mississippi Delta. Risk factors for cervical cancer include persistent infection with oncogenic types of human papillomavirus (HPV) and lack of effective screening for precancerous lesions. A recent study has determined that testing of cervical vaginal cells for HPV DNA may be an effective alternative to Pap smear screening. The lack of dependence on trained pathologists to read the results of this test may make it an effective prevention strategy for underserved populations. In this regard, DCEG has recently initiated a collaborative study with CRCHD in the Mississippi Delta to evaluate the effectiveness of HPV screening of self-collected specimens. This approach may provide wider coverage of this underserved population.

DCEG is also involved in the development of various consortia, which are large-cohort, case-controlled studies of large, diverse populations. These endeavors are highly collaborative, involving epidemiologists as well as clinical and molecular scientists. They collect information on diet, lifestyle, occupation, and environmental exposures. They also collect biological specimens to perform genomic, proteomic, and metabolomic studies. These consortia provide an ideal structure to research cancer health disparities.

In collaboration with DCCPS and CRCHD, DCEG coordinates a fellowship program in cancer health disparities. The program provides a comprehensive training experience that includes epidemiologic and interdisciplinary research into the causes and mechanisms underlying cancer health disparities. Fellows are also exposed to translational research and its application to health care practices and policies designed to overcome disparities.

**Division of Cancer Prevention: Resources for Health Disparities Research**

*Worta McCaskill-Stevens, M.D., M.S., Program Director, Division of Cancer Prevention, NCI*

The Division of Cancer Prevention (DCP) is directed by Dr. Peter Greenwald. More information about the research and activities of DCP can be found at [http://www.cancer.gov/prevention](http://www.cancer.gov/prevention).

DCP supports a variety of funding mechanisms, including U10 cooperative agreements, contracts, and investigator-initiated awards. It also supports minority administrative supplements. The goals of DCP are to identify persons who are at risk for cancer and determine where individuals are in the process of carcinogenesis. The Division also seeks to define ways to prevent and slow carcinogenesis as well as reduce cancer risk. The activities of DCP span the cancer continuum, focusing on detecting cancer at its earliest stages as well as supporting symptom management and end-of-life care.

To address its goals, DCP works to generate new information about molecular processes that are amenable to intervention. It is involved in the development of chemopreventive agents and the search for early detection biomarkers as well as the testing of new screening methods and technologies. The Division also supports work to identify mechanistically targeted nutrients. In addition to its basic research activities, DCP trains physicians and scientists in cancer prevention research and conducts a variety of Phase I, II, and III clinical trials in cancer prevention and control at the community level.
DCP is composed of a number of research groups, including Basic Science Prevention, Cancer Biomarkers, Nutritional Science, Chemopreventive Agent Development, Early Detection, Biometry, Community Oncology and Prevention Trials, and the Office of Cancer Prevention. The Community Oncology and Prevention Trials group houses the large Phase III trials and evaluates the “user-friendliness” of Phase III prevention trials that are conducted on a community basis. The Division also supports four organ-based research groups for breast and gynecological cancer, prostate and urological cancer, lung and upper aerodigestive cancer, and gastrointestinal cancer. The organ-based groups are funded through Phase I and Phase II contracts.

A number of DCP programs have a significant impact on cancer health disparities. Of the 63 Community Clinical Oncology Programs (CCOPs), 11 are Minority-Based CCOPs; in order to be classified as such, 40% of the catchment population must be members of minority groups. Approximately 60% of those accrued for clinical trials participation through the Minority-Based CCOPs are minorities. DCP also places high priority on studying estrogen receptor-negative breast cancer, which has a high incidence rate among young African American women.

Another area of high priority is Phase III clinical trials. Two large Phase III trials in prostate cancer and two in breast cancer have been completed; a third breast cancer trial is currently in the planning stages. All of the DCP-sponsored Phase III trials submit tissue and serum to biorepositories, which are a tremendous resource for additional studies. More information regarding access to tissue banks is available from DCP. The trials supported by DCP have demonstrated variable recruitment of minority participation: SELECT (Selenium and Vitamin E Cancer Prevention Trial) accrued 15% minorities; the breast cancer prevention trial included 3% minorities; and the recently published STAR (Study of Tamoxifen and Raloxifene) trial had 6% minorities.

DCP also focuses on early detection research. The Division’s Early Detection Research Group housed the large Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO); of the over 170,000 participants in this trial, 15% were African American. The Division also has a number of trials examining symptom management at the community level, including efforts to compare differences between various geographic and ethnic populations.

The Cancer Prevention Fellowship Program is a very high priority for DCP. Fellows earn a Master of Public Health degree and perform 3 years of mentored research at NCI. Between 1987 and 2005 the program trained 176 fellows, 31% of whom were minorities. DCP also offers a comprehensive Summer Curriculum in Cancer Prevention.

Enhancing Interactions across NCI to Reduce Cancer Health Disparities
C. Norman Coleman, M.D., Division of Cancer Treatment and Diagnosis, NCI

The Division of Cancer Treatment and Diagnosis (DCTD) is led by Dr. James Doroshow. Primary contacts for DCTD programs include Drs. Michaele Christian and Ted Trimble for the Cancer Therapy Evaluation Program (CTEP) and Dr. Frank Govern for the Radiation Research Program (RRP).

One of the goals of CTEP is to overcome barriers to early-phase clinical trials. In collaboration with the Foundation for NIH, CTEP has developed a new way of doing public/private partnerships and is working with a number of companies to evaluate new models to overcome barriers, particularly those experienced by minority and older populations. Additional CTEP projects that are attempting to overcome barriers are the Patient Navigator and Coach Programs at Massachusetts General Hospital and Washington University; outreach to community hospitals being done by Massachusetts General Hospital and the University of Pittsburgh; and the Physician’s Incentives Programs at the University of Pittsburgh.

CTEP is involved in medical informatics projects at the Ohio State University and the University of Pittsburgh to identify potentially eligible patients for clinical trials and match these patients with open
trials. CTEP is also working to improve the informed consent process for patients not fluent in English; this project includes educating translators about clinical trials and the use of a short-form consent document, oral translation, and videotapes. Additional CTEP projects relevant to health disparities involve educating patients, physicians, and the general public about clinical trials and assessing barriers of Hispanics and the elderly related to clinical trials participation. A physician communication module that provides training for research nurses and data managers in informatics for clinical trials support has been used at Howard University Hospital and Meharry Medical College, both of which are successful Minority-Based CCOPs.

The NCI-supported cancer treatment network is composed of 3,300 clinical sites. The clinical enterprise enrolls 25,000-30,000 patients to clinical trials each year.

The RRP’s Cancer Disparities Research Partnership Program is a $25 million, 5-year project. The goals of the CDRP are to increase minority representation on clinical trials; increase the number of clinical and translational scientists studying cancer disparities; develop institutions embedded in minority communities for long-term research efforts; explore the applications of telemedicine; investigate new areas of clinical and social health disparities research; and help these sites become competitive for future funding. The CDRP is utilizing the Telesynergy Suite, a high-tech communications system that was developed by the Center for Information Technology. This system allows six to eight centers to conference with one another in a highly interactive way.

The Cancer Expert Corps (CEC) is a new initiative that will be launched relatively soon. The mission of CEC is to bring quality cancer clinical trials to disparity populations worldwide by developing expertise in the conduct of clinical, protocol-based research. The program will provide infrastructure and technical assistance, and coordinate public-private organizations in order to establish regional, national, and international networks of cancer professionals.

**Key Points of Discussion**

**NIH/NCI Funding Community: Our Investment in Disparities Research (Part I)**

- **Clinical Trials Accrual.** In the past, there has been substantial difficulty recruiting African American women for breast cancer prevention trials. One reason that African American women have been underrepresented in prevention trials is that the trials have focused on postmenopausal risk; postmenopausal risk of breast cancer among African American women is actually relatively low. Other reasons underlying low enrollment of African American women in these trials are stringent eligibility criteria and low referral rates. To address the former, efforts have been made to accumulate data regarding attributable risk in African American women; incorporation of these risk factors into the Gail Model increases the likelihood that these women will meet the eligibility criteria for clinical trials. Efforts have also been made to educate primary care physicians about risks and benefits of prevention in hopes that this will increase clinical trials referral rates.

- **Evaluation.** The importance of identifying appropriate metrics to evaluate the effectiveness of programs was emphasized, although it was recognized that it is often difficult to measure things such as quality of care and incorporation of new groups into the cancer enterprise. One criterion for evaluation is the successful translation of discoveries to effective applications. There are currently a number of collaborative processes under way to develop statistically validated consensus measures to evaluate quality of cancer care for more common cancers, such as colorectal cancer; it was predicted that standardized performance measures would emerge in the next few years. NCI has also been working with CDC and the Centers for Medicare and Medicaid Services (CMS) to develop sound metrics for evaluation so that the Federal health system can more effectively perform evaluation and delivery of health care interventions. The ultimate outcome measure is the reduction of health disparities and the improved health of individuals in our communities. In this regard, it is critically important that researchers establish baseline data so that they can document the impact of their
interventions. The health disparities research community must strive to actually measure the
difference it is making in the lives of people in the community rather than the number of publications
it generates. The NCI recently published a monograph on health disparities assessment at the
population level, which is available from NCI at no charge.

Training. The Comprehensive Minority Biomedical Branch (CMBB) funds a number of minority
supplements for training, which can be awarded to investigators with NCI funding from any Division
or Center. CMBB also sponsors Minority K awards. The NIH Pathway to Independence award
provides a mechanism by which students can transition to faculty positions.

NIH/NCI Funding Community: Our Investment in Disparities Research (Part II)

Moderator: Michaele Christian, M.D., Division of Cancer Treatment and Diagnosis, NCI

Eliminating Health Disparities: Community-Based Participatory Research and Loan
Repayment Program

Francisco Sy, M.D., Dr.P.H., Chief, Office of Community-Based Participatory Research and
Outreach, NCMHD

Two of the programs sponsored by NCMHD are the Community-Based Participatory Research (CBPR)
initiative and the Loan Repayment Programs (LRP). The NCMHD CBPR program defines CBPR as a
collaborative approach to research that equitably involves all partners in the research process and
recognizes the unique strengths that each brings. CBPR should begin with a research topic of importance
to the community with the aim of combining knowledge and action for social change to improve
community health and eliminate health disparities. The adoption of this model for health disparities
research has been driven by a number of factors. The complex health and social problems that
characterize health disparities are ill suited for more traditional intervention research approaches, which
have yielded largely disappointing results. There has also been more demand for community-driven
research and an increased recognition of the importance of local context for health disparities research.

The NCMHD CBPR program currently has 25 grantees, two of which focus on cancer. Four CBPR
grantees have not yet determined the disease focus of their programs; this decision is supposed to be made
in concert with the community over the first year of funding of the grant. The remaining 19 programs
focus on diabetes, cardiovascular disease, hypertension, HIV/AIDS, and other diseases and conditions.
The goal of the CBPR program is to support community intervention research using CBPR principles in
order to reduce and eliminate health disparities in any disease or condition of major concern to the
community, with emphasis on racial and ethnic minorities. A key aspect of the program is the NCMHD
facilitation of interactions between the scientific and community partners through all phases of research.

The 11-year CBPR program begins with a 3-year planning grant. This is followed in sequence by a 5-year
intervention research grant and a 3-year dissemination research grant. During the first year of the planning
grant, grantees form a board and work with the community to perform a needs assessment. In the second
year, the programs begin pilot intervention studies that continue into the third year of funding. The data
generated are used to compete for the 5-year intervention research grant. The first RFA for the 5-year
phase of the program will likely be released in the fall of 2007; any program that can demonstrate that it
has done community-based planning will be free to compete for these awards even if it was not supported
by an NCMHD planning grant.

There are a number of challenges associated with CBPR. It is difficult to maintain comprehensive
community consultation throughout the entire research process. Also, many academic centers do not place
high value on the time and effort that investigators spend working with the community. Furthermore,
there is a dearth of minority researchers performing CBPR in minority communities, which contributes to
the persistence of institutional racism.

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NCMHD also supports two different Loan Repayment Programs—the Health Disparities Research LRP (HDR-LRP) and the Extramural Clinical Research LRP for Individuals from Disadvantaged Backgrounds (ECR-LRP). Participants in the programs receive up to $35,000 per year in loan relief in exchange for a commitment that 50% of their time will be spent performing research. The number of applications has increased for the HDR-LRP while the number of new applications for the ECR-LRP has decreased since 2002. The funds invested in these programs have increased from $7 million in 2002 to over $10 million in 2005. Of the over 800 scholars who have participated in these programs, 89 have done research in the field of cancer.

**NCI’s Office of Centers, Training, and Resources: Fostering Progress in Cancer Health Disparities Research**

*Ernest Hawk, M.D., M.P.H., Office of Centers, Training, and Resources, NCI*

The major goals of the Office of Centers, Training, and Resources (OCTR) include building cancer research infrastructure and capacity, primarily through the Cancer Centers Program; supporting translational cancer research, which spans all NCI Divisions, Offices, and Centers; anticipating cancer research manpower needs; and, finally, ensuring diversity among cancer scientists. The activities that address the last goal are primarily carried out by the CMBB. OCTR contributes to the strategic goal of overcoming cancer health disparities in a number of ways. It directly funds health disparities research and supports the development of institutional capacity to perform health disparities training and research. It also supports outreach and education activities that target underserved populations, as well as the training of individuals from minority/underserved groups and other professionals in the area of health disparities research.

The mission of the Cancer Centers Program is twofold: to foster excellence in research across a broad spectrum of scientific and medical concerns relevant to cancer, and to extend the benefits of research to patients, their families, and the general public through clinical care, outreach, and education. The NCI funds the first half of this mission; support is not provided for clinical care, outreach, and education, although cancer centers are expected to carry out these activities. There are 61 NCI-designated Cancer Centers, and cancer center grants accounted for $240 million of the NCI budget in 2005. Overall, approximately 50-60% of the NCI budget goes to cancer centers through a variety of grant mechanisms, including R01s and P01s. The centers span the United States, although coverage is not as optimal as desired in areas of the Midwest and Deep South.

The Specialized Programs of Research Excellence (SPOREs) strive to move promising scientific discoveries through early-phase clinical trials. SPOREs directly fund cancer health disparities research and are involved in training minorities for careers in translational research. SPOREs also attempt to expand the diversity present in tissue repositories and track minority participation in early-phase translational and clinical trials.

The Cancer Training Branch places strong emphasis on clinical research, cancer prevention and control, and behavioral and population sciences. It supports trainees through 14 different award mechanisms awarded at various career stages. Currently, the Branch does not capture information about the diversity of the awardees of these programs, but it hopes to address this in the future. Two Training Branch programs that are particularly relevant to cancer health disparities are the R25 and K07 programs.

CMBB represents OCTR’s most substantial commitment to training researchers from minority and underserved populations. CMBB strives to increase the number of competitive minorities in biomedical research; increase the competitive research capacity of minority-serving institutions; and serve as a resource and model for other programs and organizations with similar missions. The CMBB Continuing Umbrella of Research Experiences (CURE) program focuses on training representatives from underrepresented populations to become competitive cancer researchers. CURE is largely based on
supplements to a variety of different forms of grants; 377 investigators were supported through this program in 2004. The Minority-Serving Institution/Cancer Center Partnership program focuses on the institutional level. It works to increase the capacity of MSIs to perform cancer research and improve the efforts of NCI-designated cancer centers in the area of cancer health disparities.

Many cancer centers are also currently involved in the NCI-sponsored MI/CCP program. This program attempts to extend the work of the cancer centers into underserved populations, and, unlike the Cancer Center Program, does provide support for outreach, training, and education activities.

In the future, OCTR hopes to extend its work in the area of health disparities by developing databases to more effectively track and evaluate its activities in this area. This type of effort could facilitate coordination of research activities within NCI and beyond.

**NIH/NCI Extramural Funding Community: Our Investment in Disparities Research**

*Nelvis Castro, Acting Director, Office of Communications, NCI*

The United States is becoming more diverse than ever and the Federal Government has begun to place increased emphasis on the issue of health disparities. In the current climate and given today’s media tools, there are more opportunities to use communications to reach those most in need of health interventions. In addition to supporting research, the NCI also funds a number of communication and outreach activities focused on ensuring that the public, particularly minorities and underserved populations, benefit from this research. Examples of such activities include the Cancer Information Service (CIS) Partnership Program, the Minority Media Outreach, the Spanish Language Web Project, and a pilot program on cancer health disparities communications for the Nation.

The Cancer Information Service Partnership Program works closely with regional and community organizations to identify, adapt, and implement evidence-based programs. Its efforts target communities that suffer an unequal burden of cancer, including minority and medically underserved populations. The program leverages resources by establishing these partnerships and provides technical assistance to its partners in the areas of training, program planning, and evaluation. One example of a program used by CIS is the Body and Soul program, which partners with African American churches to get information to parishioners about the health benefits of a good diet. Cancer 101, another program, is a training initiative designed to raise cancer awareness and provide cancer-related education to tribal communities. Team Up is a national partnership to increase cervical and breast cancer screening among rarely or never-screened individuals. Cancer Control PLANET, which is coordinated by the Division of Cancer Control and Population Sciences (DCCPS) in collaboration with other Federal agencies and organizations, is used as a planning tool by community groups. Finally, the Train the Trainer course is designed to improve dissemination of educational programs to the community.

The Minority Media Outreach program is based on the fact that ethnic media reach 25% of the entire U.S. population and 80% of adults in minority communities. For example, Spanish-language media is the fastest growing media in the U.S. As a result, NCI’s Minority Media Outreach program targets bilingual newspapers as well as Spanish-language radio and TV. It also enlists the involvement of NCI’s minority and other scientists as spokespersons and utilizes Spanish-language writers and editors. Radio has proven to be the most cost-effective medium to use, as a large number of listeners and stations in multiple markets can be reached by conducting just one interview.

As the number of Hispanic Internet users continues to increase, the Internet is also being used as a media outlet to reach Spanish-speaking populations. The NCI Office of Communications has initiated the Spanish-language Web Project to build a Spanish-language version of the NCI Web site. This new Web site is scheduled for launch in early 2007.
The Office of Communications is also involved in the Centers of Excellence in Health Communications Research grant program. It hopes to use the research being carried out as part of this program to shape the way NCI reaches out to the community.

The Office of Communications has initiated a pilot program on cancer health disparities communications coordination as part of the NCI Strategic Plan. This 2-year effort is designed to manage the planning and integration of communications activities across the NCI.

There are numerous ways in which grantees can work with the NCI Office of Communications. The Office has developed a roster of spokespersons from the grantee community who can talk to the media about cancer health disparities and minority outreach. Grantees are also helpful in keeping NCI abreast of news or feature opportunities that may be of interest to minority audiences. The Office also actively advises grantees how to present their information in appealing and culturally sensitive ways when they serve as sources for local media outlets.

**Enhancing Interactions to Reduce Cancer Health Disparities**

*Samir Sauma, Ph.D., Office of Science Planning and Assessment, NCI*

Dr. Sauma presented on behalf of Cherie Nichols, Director of the Office of Science Planning and Assessment (OSPA), who was unable to attend the Summit.

NCI is employing a number of approaches to achieve the vision of eliminating the suffering and death due to cancer, including strategic planning, the development of strategic priorities, and the formation of Integration/Implementation (I²) Teams. Other major efforts to reach this goal include the Clinical Trials Working Group, the Translational Research Working Group, various think tanks, and the Food and Drug Administration (FDA) and CMS Task Force.

The NCI strategic planning process progresses through thinking, planning, and doing phases. The process begins with strategic exploration, which leads to strategic assessment, strategic planning, operational planning, and implementation. This sequence of events is utilized to generate NCI strategic plans and priorities, including the long-range 5-year strategic plan as well as annual strategic plans. Implementation of the strategic plans depends on approval by the NCI Executive Committee. NCI recognizes a number of key partners in its efforts to achieve its strategic mission, including advisory boards, advocates, cancer researchers, government leaders, the President, Congress, professional societies, and the public.

In 2002, NCI identified eight strategic initiatives, one of which was overcoming cancer health disparities. This issue is also included on the refined list of seven strategic priorities that was finalized in 2004. The formal goal is to overcome the unequal burden of cancer experienced by various population groups by discovering the fundamental causes of cancer health disparities, developing effective interventions to reduce those disparities, and facilitating intervention delivery.

The strategies defined to address cancer health disparities include identifying factors that cause cancer health disparities; developing community-based interventions; enhancing the integration of cancer services; preparing a cadre of researchers and clinicians; developing innovative and appropriate approaches to disseminating research results; and identifying a role for health policy in reducing and eliminating cancer health disparities.

Several other NCI objectives strive to ensure the best outcomes for all. These include improving the quality of life of cancer patients, survivors, and their families; improving the quality of cancer care; and understanding the factors that influence cancer outcomes. More information about NCI priorities and objectives can be found in the *NCI Strategic Plan* and *The Nation’s Investment in Cancer Research*, NCI’s annual planning document.
I² Teams are advisory subcommittees to the NCI Executive Committee. The Teams comprise representatives from across NCI, and NCI leadership selects the Team chair. Strategic leadership for I² Teams is provided by NCI Deputy Director Dr. Mark Clanton, and the activities of these teams are coordinated by OSPA. Although I² Team implementation planning takes place within NCI, the community participates in the execution of plans formulated by these Teams. The formation of a Health Disparities I² Team, which will be led by Dr. Sanya Springfield, was approved in 2005. Other current I² Teams focus on Imaging and Bioinformatics. The former Lung Cancer I² Team is now the Lung Cancer Program.

The roles and responsibilities of the I² Teams include the following: integrate, refine, and clarify existing plans and priorities; select mission-critical objectives and milestones; specify desired outcomes; develop annual and strategic plans; identify resources needed; propose initiatives/concepts that fill critical gaps or provide significant opportunities; facilitate implementation; and communicate and disseminate results and findings.

Phase I of the I² Team process is integration. This involves creating an inventory of current investment in the area of interest as well as analyzing and reviewing this portfolio. NCI Divisions are surveyed to ascertain related areas of new investment and potential collaborations are identified. The Health Disparities I² Team has accomplished these objectives and is ready to carry out the final step in the first phase of the I² process, which is the development of a plan for consideration by the Executive Committee. This plan will include activities ready for immediate implementation, identify links with other strategic areas, define outcomes and measures, and describe timelines and required resources for implementation.

Once the Executive Committee approves the plan, the second phase of the process, implementation, will be initiated. More information on this process and OSPA can be found at http://planning.cancer.gov.

**Center for Cancer Research: Our Investment in Cancer Health Disparities**

*Robert Wiltrout, Ph.D., Director, Center for Cancer Research, NCI*

CCR is a comprehensive translational research program that seeks to take basic science discoveries to clinical trials as rapidly as possible, in part through the use of biomedical technologies and other infrastructure. The basic and clinical science components of CCR are directed by Dr. Wiltrout and Dr. Lee Helman, respectively. Dr. L. Michelle Bennett, CCR Associate Director for Science, assists in the integration between these two arms of research. Efforts within the Center are divided between discovery, translational, and clinical cancer research as well as HIV/AIDS research. The Center has developed expertise in the identification of molecular targets, molecular biology, immunology, and a number of other critical areas. Training is a central part of CCR activities that spans all of these areas.

CCR contributes to the NCI mission of eliminating the suffering and death due to cancer in a number of ways. It integrates basic discovery with cutting-edge technologies to create novel approaches for the prevention and treatment of cancer. The Center also provides leadership and innovation in the area of clinical trials development and execution. The unique environment of CCR provides a venue for training the next generation of interdisciplinary basic and clinical researchers. Finally, CCR works to establish partnerships with extramural organizations and private enterprise with the goal of accelerating the translation of new discoveries and technologies to clinical application.

The NCI intramural clinical program is not a large-volume, full-service cancer center, but rather focuses on performing and extracting maximum information from small, patient-intensive clinical trials. It is hoped that the results of intramural NCI research will inform subsequent phases of clinical trials development that are carried out in the extramural cancer community, including academic medical centers and private enterprises.
CCR has contributed to a number of basic science discoveries that have been advanced to reduce cancer health disparities. It has played a role in the recent development of the vaccine against the human papilloma virus (HPV), which should have a broad impact on the incidence of cervical cancer over the next several years. CCR scientists played a central role in the creation of an immunogen that would eventually serve as a springboard for the vaccine. Animal studies within NCI also validated the potential of the HPV vaccine before the technology was licensed to Merck and GlaxoSmithKline.

The NCI intramural program has also been heavily involved in the development of HAART (Highly Active Anti-Retroviral Therapy), a combination therapy for the treatment of AIDS. As a result of this therapy, AIDS patients are living longer. Consequently, there has been an increase in AIDS-associated malignancies. Research on these malignancies is a major area of focus within the CCR.

CCR engages in a number of other research areas that are relevant to health disparities. A collaboration between CCR and Department of Defense scientists has revealed that underlying molecular differences may explain the disparities in survival observed between African American and Caucasian women with endometrial cancer. The Center also has a mandate to study rare cancers and rare diseases that are often associated with disadvantaged populations.

The Cancer Research Interns in Residence (CRIR) program was initiated in 2004. The program brings in young scientists from underrepresented or disadvantaged backgrounds across the country and provides them the opportunity to have a research experience within the NCI intramural program. The objective of the program is to increase the diversity of CCR trainee applicants.

**Key Points of Discussion**

**NIH/NCI Funding Community: Our Investment in Disparities Research (Part II)**

- **Funding for Community Partners.** There has been concern that a disproportionate amount of the funding provided for community partnerships is directed to the academic partner rather than the community partner. When it issued its RFA, the NCMHD CBPR program strongly encouraged different types of groups to apply. Two or three of the 25 funded programs are community-based organizations, not academic centers. Community-based organizations need to be encouraged to take the lead on more proposals and engage academic centers as partners rather than the other way around. The MI/CCP program is based on the notion that the MSI and the cancer center are equal partners; thus, each institution is issued a separate grant. This premise was developed based on years of experience of the Comprehensive Minority Biomedical Program.

- **Minority Recruitment to Clinical Trials.** Inadequate accrual of minorities to clinical trials has been a persistent problem. The Upper Cardozo clinic is addressing this issue, although it is still too early to tell whether it will affect recruitment of minorities to clinical trials. One approach under way at the clinic is the education of community physicians, who can play a large part by referring patients to clinical trials for which they may be eligible. Although the cancer centers have not been very successful to date recruiting minorities to clinical trials for a number of reasons, the issue is beginning to be taken more seriously in peer review. Training is also tremendously important for improving minority recruitment to clinical trials; researchers and clinicians from minority and underserved populations will likely be able to more effectively communicate with members of these populations and attract them to participate in clinical research.

- **Training of Volunteers.** Training is important not only for researchers and clinicians, but also for volunteers working against cancer health disparities. Survivors, patients, and other volunteers are an important part of the cancer enterprise, and training would increase the utility and acceptance of these individuals by other parts of the cancer research community. Community leaders and cancer survivors should also be trained to be spokespersons on behalf of both their community and cancer research. In this regard, the Loma Linda University School of Public Health, a Project EXPORT site, has
developed a community-based educational model that targets African American men and addresses prostate cancer prevention. So far, the program has been very successful.

- **Culturally Appropriate Language.** Cancer materials and information need to be made available in a language that is relevant to African Americans. Terms such as “screening,” “clinical trials,” and “online” may be meaningless or carry different implications in African American communities than in other populations. More traditional approaches, such as single pages of information distributed in the church parking lot on Sunday morning, need to be adopted to ensure that some groups of people are not left behind.

- **Funding for Nonresearch Activities.** Many community programs that do not perform research activities are at risk for losing their funding. For example, programs funded by tobacco restitution funds may not be guaranteed continued funding. Support for nonresearch activities is critical. Although some communities are not ready to engage in research, investment in nonresearch activities will foster trust within the community and may lead to research opportunities in the future. Nonresearch activities are supported through the MI/CCP program; however, these funds are only available to program affiliates. There may be opportunities for community programs to partner with Project EXPORT sites in order to gain support for outreach activities. Also, community programs could seek opportunities to secure funds from other Federal agencies, such as CDC, whose missions are less research focused than those of NIH and NCI.

- **Timeframe of the NCMHD CBPR Program.** The CBPR program recognizes that working with community partners takes a long time. It was designed to allow ample time over the first year of funding to perform a needs assessment, form community advisory boards, and identify a disease focus. It seems that most of the grantees are progressing through this process quite well.

- **Junior Faculty.** Junior faculty members often do not have sufficient time to write publications and develop partnerships with other researchers. Protected time is needed to allow junior researchers to publish their research in order to disseminate their findings to the larger research community. Junior faculty and minority faculty would also benefit from increased mentoring and help in networking with other researchers. The Comprehensive Minority Biomedical Branch fosters networking and mentorship by facilitating relationships between its various awardees. This is accomplished in part through annual workshops that bring together grant recipients. However, the reach of these programs is limited to researchers who have received funding through CMBB.

**Report from the NCI-Wide Workshop: Enhancing Interactions to Reduce Cancer Health Disparities**

*L. Michelle Bennett, Ph.D., Associate Director for Science, Center for Cancer Research, NCI
Lenora Johnson, M.P.H., Director, Office of Education and Special Initiatives, NCI*

The NCI-wide *Enhancing Interactions to Reduce Cancer Health Disparities* workshop took place in November 2005 and was co-chaired by Dr. Michelle Bennett and Ms. Lenora Johnson. The purpose of the workshop was to enhance the capacity of NCI to reduce cancer health disparities by: 1) developing a consistent and sustainable multidisciplinary and collaborative effort to stimulate interactions across NCI, and 2) leveraging strengths through communication, information sharing, and partnerships. The workshop was open to all NCI staff and was attended by over 250 individuals, including NCI Deputy Directors, Executive Committee leadership, Division Deputy Directors, Lab Chiefs, Branch Chiefs, and numerous other NCI staff committed to reducing cancer health disparities.

NCI staff presented the efforts of their programs related to the reduction of cancer health disparities. Attendees also participated in a number of smaller breakout sessions to discuss specific areas relevant to health disparities research.
An evaluation of the workshop was performed by surveying meeting participants. Nearly all of the respondents indicated that the workshop goals were “fully met” or “somewhat met.” Most also considered both the plenary and breakout sessions to be valuable, although many of those surveyed indicated that they would have preferred to have more time for breakout discussions.

Prior to the workshop, the planning committee, in conjunction with OSPA, performed a portfolio analysis of NCI activities related to cancer health disparities. The portfolio review revealed that 5.6% of the total NCI budget was devoted to health disparities research in 2004. The analysis provided insight into the various types of projects being done to address cancer health disparities; however, because the current NCI coding system is not ideal for evaluating health disparities research, the detail and accuracy of the analysis is limited. The committee also asked each of the various components of the Institute to identify and describe the most effective and promising health disparities interventions they supported.

The workshop marked the first NCI-wide dialogue on cancer health disparities and provided NCI staff an overview of intramural and extramural research programs related to health disparities. The formal workshop proceedings provided feedback to the Executive Committee and other leadership and lays out a platform for NCI activities to reduce cancer health disparities. The vision that emerged from the workshop was that “the NCI will lead the Nation’s effort to eliminate cancer health disparities.” This vision is supported by six goals that were generated throughout the course of the workshop:

- Actively incorporate the elimination of health disparities into what we do.
- Define and establish health disparities as a formal research discipline.
- Align community research problems with discovery research expertise. Work with the community to learn what is needed and how best to deliver services.
- Seize the power of collaboration by effectively communicating advances in health disparities research and encouraging bold new initiatives across disciplines.
- Strive for social justice and equality.
- Fully support a diverse workforce internally and externally by training for career advancement and cultural competence.

Action plans were also developed based on the work of the seven breakout groups in the areas of genetic and biological differences; narrowing the gap between research and practice; clinical trials; sociocultural and behavioral influences; cancer care delivery; education and training; and communications research. Three major next steps emerged from the meeting:

- Elevate health disparities research across the Institute.
- Maintain momentum by continuing to communicate.
- Create an I² Team for health disparities.

The Health Disparities I² Team has since been created and will use the workshop proceedings as one of the foundations for moving forward with its charge and will drive NCI progress in the area of cancer health disparities.
Health Disparities Community Voices: Surviving the Three U’s (Underserved, Underrepresented, Underfunded)

Moderator: Louis W. Sullivan, M.D., President Emeritus, Morehouse School of Medicine

Disparities in Cancer Incidence, Mortality, and Care in African Americans

Louis W. Sullivan, M.D., President Emeritus, Morehouse School of Medicine

Disparities have been identified across a wide range of disease areas and clinical services. Health disparities persist in African Americans even when factors such as socioeconomic status, education level, age, and severity of disease are taken into account.

A number of landmark publications and events have addressed cancer disparities in black populations over the past several decades. A 1974 report from Dr. LaSalle Leffall and his colleague Dr. Henschke highlighted the alarming cancer death rates that were occurring in African Americans. The Task Force on Black and Minority Health commissioned by Secretary of HHS Margaret Heckler in 1984 reported that African Americans had higher incidences of disease and disability and shorter life spans than whites. Also, 1984 marked the first NCI intervention trial designed to address tobacco use and cancer screening in the African American population. In 1985 NCI expanded its efforts to report cancer incidence by race. A few years later, in 1989, the National Black Leadership Initiative on Cancer was initiated.

A number of factors contribute to cancer disparities in African Americans. These include lifestyle, environmental factors, inadequate levels of insurance, as well as low levels of participation in the health care system. Many African Americans delay entering the health care system when they begin to develop symptoms, a behavior that contributes to some of the increased cancer mortality rates experienced by this population.

Cancer incidence and mortality rates are higher among black men than white men at all ages. Although cancer incidence is lower among black women than white women, black women experience significantly higher mortality rates due to cancer. The reduced survival rate observed in blacks exists whether the cancer is localized, regional, or distant.

Although improvements have been made in cancer survival in all populations, disparities in cancer outcomes continue. Efforts must continue to reduce the gap in cancer mortality between blacks and whites.

Health Disparity and Cancer: Voices from Native American Communities

Jennie R. Joe, Ph.D., M.P.H., Director, Native American Research and Training Center

Health disparities should be considered in the context of social justice. Margaret Whitehead stated that health inequities are “differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and unjust.” Implicit in this definition are the notion of power and the concept of sharing resources, which is necessary to make progress in this area.

For many years, the short life expectancy of Native Americans led some to conclude that the population did not experience common diseases such as cancer. In fact, Native languages did not have a word for “cancer.” However, cancer is now known to be the leading cause of death for Native Americans over the age of 45.

There are regional differences in cancer statistics among Native populations. This knowledge would not be available if we had not paid close attention to issues of cancer data collection. Alaska Natives have the highest mortality of all racial groups for all cancers combined. Some of these disparities are due to the health delivery system in Native communities. Often, little attention is paid to chronic disease; rather, the
system is designed to address the needs of acute illnesses. Little attention has been paid to cancer until relatively recently, in part because diagnostic and treatment tools have not been readily available in these communities.

Who suffers when resources are underfunded, when communities are chronically underserved, and when individuals are members of populations that have been historically underrepresented? Among those who are affected are our family members, our friends, our neighbors, our communities, and ourselves.

When a New Mexico Pueblo woman was diagnosed with leukemia in 1987, she was sent to Los Angeles for a bone marrow transplant. She was reluctant to leave her three children, who ranged in age from 3 to 7 years, but there were no resources near her home so she went. This woman did not deal with her cancer diagnosis and treatment passively. When she returned home she made people in her community uncomfortable by talking about her cancer. Most members of her community had never known someone with cancer who had survived. There seemed to be an implicit message that cancer was contagious and people were hesitant to even shake her hand or talk to her. But she decided to start a support group that became her life’s ambition and passion and turned her negative experience around to help other people. She continues to hold workshops and train other people to start their own support groups. This woman’s leukemia recurred in 2005 and she also experienced a stroke, but she is now in remission.

The first woman Principal Chief of the Cherokee Nation is also a cancer survivor and speaks about her cancer experience in a number of different forums. She often speaks to the “gift of life” she received from participating in various clinical trials. Her experience with cancer was complicated by kidney failure. As she received multiple kidney transplants and underwent treatment for cancer, her husband often turned to traditional medicine healers in various Native groups to help him and other family members support her and pray for her recovery. This was a very important resource that was accessed outside the clinical setting. This Cherokee woman likely had better access to specialty care than the aforementioned Pueblo woman because of her prominent position in the community and her understanding of the health care delivery system.

In 1990 the Native American Research and Training Center held one of the first Native American/Alaska Native cancer conferences in Tucson, which was attended by 50-60 people. At that time there were only two American Indian oncologists and very few ongoing research projects related to Native populations. Although epidemiological data and SEER data existed, there were virtually no cancer prevention activities under way.

The cancer research community has come a long way since 1990, largely due to champions within NCI and other Federal agencies. They have helped to improve the data available, making it possible to recognize things such as regional differences in cancer. They also helped establish minority cancer network groups, which have provided researchers an opportunity to meet and share data and foster community development. They have also provided resources and dollars to increase cancer awareness in Native communities. They have provided capacity building and supported prevention and intervention studies as well as patient navigation programs in special populations.

Progress can be achieved despite the three U’s by empowering communities, increasing knowledge and changing perceptions about cancer, utilizing cancer survivors, improving access to care, and improving early detection and treatment. The CDC has contributed to this progress through its willingness to work with a number of Native communities to reach women over childbearing age. Activities such as these have begun to change the perception of cancer in these communities.

There has been progress, but more needs to be done. Cancer care needs to be developed for rural communities. Work also needs to be done to promote the idea that cancer is a chronic disease; otherwise, people will think that they are well once their treatment has been completed and they will not return to the doctor for periodic checkups. There should also be increased support for activities that evaluate community-based interventions. Efforts also need to be made to promote the idea of treating the patient as
a whole person, since patients often have comorbidities that need to be taken into account. Also, the concept of ethos—the disposition, character, or fundamental values peculiar to a specific person or culture—should be incorporated into our approach to health care.

**Hispanics and Cancer Research Policy Priorities**

*Elena Rios, M.D., M.S.P.H., President and CEO, National Hispanic Medical Association*

Hispanics currently account for 14% of the U.S. population and will represent 25% of the U.S. population by 2050. Hispanics experience a number of barriers to health care, including lack of trust in the system; low socioeconomic status; inadequate understanding of written and oral information; and provider confusion and bias. Hispanics also have a very strong sense of culture, which includes a high value of family as well as a fatalistic view of cancer. Many members of the Hispanic community are strongly connected to alternative medicine and traditional healers. Language is also a very important issue for Hispanic communities and has a definite impact on their interactions with the health care system.

There are also a number of systemic barriers that contribute to health disparities in Hispanic populations. A larger proportion of Hispanics than any other population in the U.S. are without health insurance. This creates a barrier to even entering the health care system. There is also a lack of culturally relevant, culturally appropriate services, although the Office of Minority Health and grant programs within NCI have begun to address this issue. There is a dearth of Hispanic health professionals, including physicians, nurses, and dentists. Deficiencies in data collection, political participation, leadership, and funding also pose systemic barriers.

There are a number of NCI/NCMHD programs that combat Hispanic health disparities. One example, *Redes en Accion*, an NCI Community Networks Program, provides a national comprehensive approach to research, education, and training. It is conducted across multiple academic centers, each of which has regional partners. The program has developed a large knowledge base and has facilitated information exchange.

In 2004 the *Redes en Accion* network created the Hispanic Cancer Research Agenda, which laid out the following research priorities: quality of services; outreach; access and continuity; attitudes and behaviors (of both patients and providers); communications; high-risk populations; cancer survivors; Hispanic researcher development (beginning in K-12 and continuing through to junior faculty); and cultural competence training.

In September 2000 the NIH Latino Roundtable Conference generated a series of recommendations. The primary recommendation was for the formation of an Office of Latino Health within the newly formed National Center for Minority Health and Health Disparities. The creation of this Office would result in more resources devoted to Hispanic communities and promote collaborative work on Latino health issues to be done across all NIH Institutes and Centers. The Office would formulate a strategic plan for its own activities and also facilitate the development of a Latino component of the *NIH Strategic Plan*. The report further recommended that the Office oversee the development of an extramural program to address Latino health needs; perform an evaluation of current programs to determine how they target the needs of the Latino community; serve as a resource center to coordinate outreach activities; develop partnerships with Latino stakeholders; coordinate recruitment for employment and training; and form both external and NIH internal Latino advisory committees. These recommendations were not taken very far in 2000 and many of these priorities remain in 2006.

Efforts need to be made to reach the public and patients with cancer, at least in part through multimedia approaches. Information needs to be both patient centered and family centered. Efforts also need to be made to encourage Latino patients to participate in clinical trials. There is a pressing need to train junior faculty and support faculty development activities. Community-based activities are another high priority.
There is also a need for Federal agencies (e.g., NCI, NIH, HHS, the Department of Defense, the Veterans Administration) to work together. The NCI should coordinate and lead cancer research activities across all Federal and state partners. Efforts should also be made to build on successful models, such as Redes en Accion.

Consolidation is one approach to achieving the goal of eliminating cancer disparities in the face of budget cuts. Programs should focus on key stakeholders; namely, the patients. There needs to be improved coordination across Federal Government initiatives; this should begin with the recent HHS council that met to discuss disparities in health. Researchers also need to develop the political will to influence Congressmen and Senators to continue to support efforts to eliminate disparities in health. People should begin to think about the formation of a minority cancer coalition in Washington, DC, which has never existed.

The mission of the National Hispanic Medical Association (NHMA) is to improve the health of Hispanics and the underserved. NHMA partners include its Council of Medical Societies and all the national Hispanic health professional societies. NHMA has a foundation that is currently developing research and scholarship programs in affiliation with the Robert F. Wagner Graduate School of Public Service at New York University. The NHMA Web site is http://nhmamd.org. NHMA has also created a portal for Hispanic health information that can be found at http://HispanicHealth.info.

Health Disparities Community Voices: Surviving the Three U’s
Ho Luong Tran M.D., M.P.H., President and CEO, Asian & Pacific Islander American Health Forum

The mission of the Asian and Pacific Islander American Health Forum (APIAHF) is to enable Asian Americans and Pacific Islanders (AAPI) to attain the highest possible level of health and well-being. It envisions a multicultural society in which Asian American and Pacific Islander communities are included and represented in health, political, social, and economic areas and in which there is social justice for all.

There are currently an estimated 13.5 million U.S. residents who say they are Asian or Asian in combination with one or more other races; 8.7 million of these were born in Asia. The number of Native Hawaiian and Other Pacific Islanders (NHOPI) is just under 1 million. Together, Asians and NHOPI comprise about 4% of the U.S. population. However, while the total U.S. population has only grown by 13% since 1990, the total Asian population has grown by 72% and the NHOPI population has increased by 140%.

Several subsets of the Asian and NHOPI populations demonstrate a much lower per capita income than that of other sectors of the United States. Asian Americans are often viewed as a model minority group, but this population displays bimodal income characteristics—some Asian Americans are wealthy while others are poor and very much underserved.

There is also a disparity in the level of education of some sectors of the Asian population. While only 20% of the overall U.S. population have less than a high school diploma, nearly half of Hmong, Cambodian, and Laotian populations do not complete high school. Furthermore, a smaller percentage of Asian and NHOPI earn a bachelor’s degree than the U.S. population as a whole.

There are two important components of disparities in health status. One is access to care, which is strongly associated with health insurance status. When the AAPI population is considered as a whole, its rate of uninsurance, 21%, is not tremendously different from the rate of the non-Latino white population, 14%. However, Koreans have an uninsurance rate of 34% and in some states this rate rises to 40%. The second important component of disparities in health status is quality of care. As defined by the Institute of Medicine in their 2001 report, quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current
professional knowledge. These outcomes can be measured to some degree by the utilization rates for various medical procedures, which are influenced by cultural competence and linguistic access. The IOM report found that numerous studies document significant racial differences in the receipt of appropriate care, including care for cancer.

Numerous disparities exist in cancer screening activities for AAPI populations. Among Asian Americans, 54% of women age 40 and over have not had a mammogram in the past 2 years. Only 48% of Filipina and 41% of Korean women receive Pap smear tests; consequently, Southeast Asian women tend to have more severe cases of cervical cancer due to late diagnosis and are less likely to undergo follow-up treatment. Also, only 25% of Filipina and 38% of Korean women receive timely colorectal cancer screening. Cancer has been the leading cause of death for female Asian Americans since 1980. The cervical cancer incidence rate is five times higher among Vietnamese women and 75 times higher among Marshall Islander women than among white women. Endometrial cancer incidence is highest in Hawaiian, Japanese, and white women ages 30 to 54. Breast cancer mortality is the third highest in the Nation among Native Hawaiians. AAPIs account for more than half of the 1.3 million cases of chronic hepatitis B and more than half the deaths resulting from chronic hepatitis B infections in the United States. Liver cancer is the third most common cancer in Asian Americans, with incidence rates 1.7 to 11.3 times higher than rates observed in white Americans. Lung cancer rates are 18% higher among Southeast Asians than among white Americans and this difference increases if different sectors of the Southeast Asian population are considered separately. The lung cancer mortality rate in Native Hawaiian men is second only to that of African American men. American Samoan men in Hawaii and California are 10 times more likely to have nasopharyngeal cancer, seven times more likely to have liver cancer, and three times more likely to have stomach cancer than white American men.

There are also disparities in quality of care. When surveyed, 40% of Asians felt that they were treated with disrespect during their interactions with the health care system, compared with only 23% of whites. Fifty-one percent of Asians felt that their doctors did not understand their background and values, compared with only 40% of whites.

There are also disparities in data collection for AAPI populations. Of the 22 objectives set forth by Healthy People 2010, only three comply with the Office of Management and Budget and only six have aggregated AAPI data. Five of these objectives have data for Asians, but not for NHOP, while an additional eight do not have statistically reliable aggregated AAPI data. Furthermore, AAPI-specific health projects represented fewer than two-tenths of a percent of the total number of Government grants between 1997 and 2000. A 2002 study found that of the millions of Medline citations, fewer than 400 had data relevant to the health of AAPI in this country.

The AAPI community has also identified deficiencies in resources. Chamorro cancer survivors have reported a lack of resources that can assist with information regarding cancer support groups, financial assistance, and post-cancer-treatment-related complications and recurrences. There is also a lack of information for spouses and children to help them better understand cancer, deal with fear and denial, and learn to provide support to the patient. Samoan cancer survivors have reported on the financial hardship of living from paycheck to paycheck and the fear of telling others about a cancer diagnosis. These survivors also reported fearing loss of employment and housing, and having concerns about the future for their families and children.

The recommendations from AAPI cancer survivors and advocates include:

- Increase access to free or inexpensive services and resources (education, prevention, screening, early detection, treatment, survivorship, and end of life).

- Increase programs that address financial barriers for care.

- Increase availability of information and education, specifically for families and caregivers.
Advocate to provide other services related to cancer support.

Advocate for increased coverage of cancer screening by insurance companies and access to services for the uninsured.

Develop stronger advocacy efforts, to be spearheaded by physicians and other health care providers.

Increase cultural competency of AAPI communities at all levels of cancer services and programs.

Develop AAPI-specific cancer support groups throughout the United States.

As an underfunded, underrepresented, and underserved population, the AAPI community has identified several questions for the Federal Government with respect to its efforts to address cancer health disparities:

- How have AAPI cancer health disparities been worked into recent NIH/NCI Requests for Proposals?
- What is the track record of NIH/NCI for awarding grants on this issue?
- What is the commitment to translation of these clinical findings into practice?
- Are there any advisory committees on which AAPIs could seek representation?
- What is available in the way of linguistically accessible telephone services under Federal Government clearinghouse agreements?
- Do Medicare-eligible physician directories list the linguistic competence of health care providers?
- Are there some cancers (e.g., liver cancer) for which we should be demanding redoubled efforts (e.g., increased hepatitis B vaccination)?

Asian Americans and Pacific Islanders need to be included in programs that target minorities, particularly those within NIH. There is also a need to recruit bilingual researchers and conduct research in the language of the community. Validated translations of survey questions and instruments must be disseminated. There should be an effort to build the capacity of community-based organizations to participate more fully in academic research. Young professionals should be recruited into and supported in careers in health disparities research. Finally, collaborations and networking across disciplines should be strongly supported.

Key Points of Discussion

Health Disparities Community Voices: Surviving the Three U’s (Underserved, Underrepresented, Underfunded)

- Investment in Health Disparities Research. There was discussion about that fact that although 30% of the U.S. population is composed of minorities, only 5.6% of the NCI budget is devoted to health disparities research. The Federal effort to address health disparities is relatively early in its development. Investment in this issue has increased over the past several years; for example, the Office of Research on Minority Health was elevated to the National Center on Minority Health and Health Disparities in 2000. However, the issue does require more emphasis and more resources.
Overview of Participating Programs (Part I)

Moderator: Francisco Sy, M.D., Dr.P.H., Office of CBPR and Outreach, NCMHD

Developing More Effective Clinical Research Models to Address Cancer Disparities in the United States

Frank Govern, Ph.D., Cancer Disparities Research Partnership Program, NCI

Minority participation in clinical trials is not in proportion with the U.S minority population. While overall participation on clinical trials has increased over the past several years, the number of minority participants has stabilized, which translates into reduced representation of minorities on these trials; this illustrates the need to increase enrollment of individuals from minority populations on clinical trials. The challenge is to create unique, nontraditional research models and funding mechanisms to accelerate research discoveries in minority populations and translate those discoveries into clinical delivery for those populations.

To accomplish this, the Cancer Disparities Research Partnership program changed the funding paradigm. Rather than using the traditional mechanism whereby community hospitals receive NCI funds through regional cancer centers, CDRP awards funds directly to the community hospitals that serve minority populations. The community hospitals then form a partnership with a Comprehensive Cancer Center that serves its needs. The goals of the CDRP program are to increase minorities on clinical trials; increase the number of scientists studying cancer disparities in the community setting; develop new institutions embedded in minority communities for long-term research efforts; explore the applications of telemedicine; investigate new areas of clinical and social health disparities research; and bring grantees to a competitive level to apply for ongoing funding. The target populations for the CDRP are African Americans, Native Americans, Asians, Hispanics/Latinos, Alaska Natives, Pacific Islanders, and populations with low socioeconomic status.

The CDRP funds three areas: specialized infrastructure, an administrative core, and a developmental core. The specialized infrastructure includes a telemedicine/teleconferencing system that allows the community hospital and its cancer center partner to communicate on a regular basis. The administrative core provides funds for equipment, supplies, and support personnel. The developmental core supports the research projects and also provides support for data management and research nursing as well as training and education. Outreach and clinical trials recruitment are also covered by developmental core funds.

The community hospital partner must be an NCI-designated Cancer Center or an institution that participates in a Cooperative Group. The partnership plan must be completed by the end of the first year of the grant and full implementation of this plan occurs in the second year of funding. Also during the first year, the institution begins to build a clinical trials infrastructure, refine its clinical trials protocol, and gain institutional review board (IRB) approval. Patient accrual to clinical trials begins in the second year of funding.

Community hospitals were selected for funding by the CDRP program based on multiple criteria. Institutions could not have received more than $100,000 in NCI funding in the past and had to demonstrate their potential impact in bringing minorities to clinical trials. The percentage of minorities in the population served by the hospital had to be higher than the state average and the incidence and mortality of cancer in the community had to be higher than the national average. Six community hospitals were selected to receive the first CDRP grants.

- Rapid City Regional Hospital Cancer Care Institute in Rapid City, SD. This hospital serves over 100,000 Native Americans as well as the poorest county in the Nation. It is mentored by the University of Wisconsin Cancer Center.
Laredo Medical Center in Laredo, TX. The community served by this hospital is 95% Hispanic, and 35% of the residents in the community live in poverty. The Medical Center is mentored by the University of Texas, San Antonio.

Singing River Hospital Regional Cancer Center in Pascagoula, MS. This hospital serves African Americans from the poorest counties in Mississippi as well as Mobile County, Alabama. It is mentored by the University of Alabama Cancer Center.

New Hanover Regional Medical Center in Wilmington, NC. The hospital serves nine counties in southeastern North Carolina in which 22.5% of the population are African American and 28% of the population live in poverty. It is mentored by the University of North Carolina Cancer Center.

Centinela Freeman Health System in Inglewood, CA. Forty-five percent of this inner-city hospital’s patient population are African American and an additional 45% are Hispanic. The hospital is mentored by the University of Southern California Cancer Center.

University of Pittsburgh Medical Center (UPMC)-McKeesport Hospital in McKeesport, PA. This hospital targets poor, rural areas of western Pennsylvania and inner-city African Americans of Allegheny County. Its primary mentor is the Washington University Mallinckrodt Institute.

The six CDRP sites are involved in 16 investigator-initiated clinical trials protocols and 40 Cooperative Group trials. As these sites move into their second and third years of funding, aggressive accrual of minorities to clinical trials has begun. The Centinela Freeman Health System has recruited 16 African Americans, three Latinos, three Caucasians, and one Asian to trials. This includes 15 men and eight women. The Rapid City Regional Medical Center has accrued a total of 645 Native Americans onto 21 clinical trials since the program opened in 2004.

The CDRP program will be conducting a preliminary program evaluation in 2006 and will undergo a comprehensive evaluation in 2006 to 2008. Some of the metrics that will be used are the increase in numbers of patients accrued to trials; provision of stage-appropriate therapy; establishment of additional multimodality clinics; the number of papers and abstracts co-authored by grantees; the health and activity of the institution’s affiliation with Cooperative Groups, the partner Cancer Center, and NCI; and use of the TeleSynergy system to enhance clinical decision making. The preliminary evaluation will contribute to the modification and improvement of the program and the issuance of a new RFA at the end of 2006. In 2007 an application will be submitted to NCI requesting the issuance of a competing renewal for the CDRP program. The ultimate measures of success of the program will be the development of solid disparities clinical research and the ability to secure funding past the life of the grant.

NCI Office of Communications

Mary Anne Bright, R.N., M.N., Office of Communications, NCI

The NCI Office of Communications (OC) represents NCI on press-related public information and communication planning matters. The Office works with both internal and external groups to communicate NCI research findings and uses technology to ensure rapid and accurate communication with NCI stakeholders. It also works to ensure that NCI speaks with a consistent and wide-reaching voice.

The National Cancer Act of 1971 mandated that NCI establish an information dissemination program, and the 1974 amendment to the Act authorized expanded information dissemination activities targeted at scientists, health professionals, and the general public. Later legislative measures expanded NCI’s information dissemination program even further.

Within the OC there is an Office of the Director that oversees the administration of the Office and plays a key role in planning and support of NCI, the NCI Director, and the NCI Deputy Directors. The Office of the Director performs communications planning and coordinates NCI trans-Divisional communications.
activities. It also handles issues, or crisis, management and releases the weekly NCI Cancer Bulletin.

There are four Offices beneath the Office of the Director: the Office of Cancer Content Management, the Office of Cancer Information Service, the Office of Technology Strategy and Applications, and the Office of Media Relations and Public Affairs.

The Office of Cancer Content Management oversees the development, publication, maintenance, and updating of the majority of cancer information products that are disseminated by the OC. This includes Web-based resources and printed materials. The Content Management team also creates content for the PDQ Clinical Trials Database and manages the clearance process for NCI. In addition to providing writing and editing support to the OC, the team is working to develop a cancer content management system to ensure that cancer information released by NCI is consistent.

The Cancer Information Service provides up-to-date, accurate, cancer-related information to patients and their families as well as health care professionals and the general public through a network of regional offices across the United States and its territories. CIS was established in 1975 and accepted its first phone call in 1976; it celebrated its 30th anniversary this year and has become one of the longest-running service-based programs at NCI. The CIS can be accessed by telephone by calling 1-800-4-CANCER or through the NCI Web site, which supports interaction with a cancer information specialist through instant messaging. The CIS mission is to be the foremost source for the latest and most accurate cancer information by connecting with people in a variety of ways, including providing one-on-one contact, working with organizations, and participating in cancer research efforts. There are 15 CIS contracts, including four coordinating centers. To effectively reach minority and underserved populations, CIS forms partnerships with organizations with missions and programs that closely match its own. The goal of these partnerships is to leverage resources to more effectively address health disparities. CIS is currently partnering with CDC and the American Cancer Society (ACS) to work on cancer control activities. The National Network of Tobacco Cessation Quitlines Initiative is a joint effort with CDC. This program, which began in 2004, established a single national access number—1-800-QUIT-NOW. Over 350,000 calls have been taken since November 2004 without any national promotional activities. CIS is working with the states to coordinate both national and regional promotion for the quit line.

The Office of Technology Strategy and Applications is responsible for designing, developing, and implementing innovative communication technologies for the Institute. This Office is responsible for the design and development of the NCI Web site (http://www.cancer.gov) as well as Web sites for the various Divisions, Offices, and Centers. It also supports the Director’s Corner, a message from the NCI Director’s Office.

The Office of Media Relations and Public Affairs works to promote public understanding of the ongoing research within NCI as well as NCI priorities. It accomplishes this in part through relationships with journalists, opinion leaders, decision makers, and the scientific community. This Office fields press calls, coordinates media events, and performs media training for NCI staff. They also coordinate two Web sites for use by the media and conduct science writer seminars throughout the United States aimed at bringing the latest cancer information to journalists. The Media Relations component of the Office also operates the Minority Media Outreach Program. Public affairs activities include the NCI exhibit program; the Health Communications Internship Program; the NCI Speakers Bureau; and the NCI Weekly Event-Cal.

Overview of the Centers for Population Health and Health Disparities
Shobha Srinivasan, Ph.D., Health Disparities Research Coordinator, Division of Cancer Control and Population Sciences, NCI

Healthy People 2010 defines health disparities as, “differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in
the United States. These population groups may be characterized by gender, age, ethnicity, education, income, social class, disability, geographic location, sexual orientation.”

Race classifications are based on the concept that racism has been associated with fewer social, educational, and economic opportunities; greater exposure to stress and unsafe environments; and reduced access to quality care. The Centers for Population Health and Health Disparities conduct research to understand the connections among biological, social, economic, and cultural factors that impact health disparities. They also attempt to understand the nature of barriers that prevent the benefits of research from reaching all populations, particularly those who bear the greatest disease burden.

Recognizing that the social determinants of health and health disparities include both proximal and distal factors, the Centers for Population Health and Health Disparities request for applications (RFA) was issued. This RFA is a collaborative effort among NCI, the National Institute for Environmental Health Sciences, the National Institute on Aging, and the Office of Behavioral and Social Sciences. It is a 5-year, $61 million commitment that is currently in its third year. The idea is to promote transdisciplinary scientific integration across various disciplines. The projects are required to have a community-based participatory research component so that the community can inform the whole scientific endeavor. Eight grants were funded:

- Katherine Tucker at Tufts University and Northeastern University is studying stressors, poverty, migration, and acculturation in the Puerto Rican population.
- John Flack at Wayne State University has focused his research on disparities in cardiovascular disease and breast cancer in inner-city African American populations.
- Nicole Lurie of the RAND Corporation has placed an emphasis on neighborhoods and determining factors that are amenable to change to inform policy for health promotion.
- Sarah Gehlert is heading a project at the University of Chicago and the University of Ibadan (Nigeria) to determine why black women in the United States and West Africa not only experience breast cancers at younger ages but why these are more aggressive than those among white women.
- Under the leadership of Electra Paskett, The Ohio State University and the University of Michigan are looking at the high incidence of cervical cancer and mortality in rural Appalachian populations.
- James Goodwin of the University of Texas Medical Branch at Galveston is attempting to identify mechanisms that contribute to lower cancer incidence in Hispanic populations.
- Timothy Rebbeck at the University of Pennsylvania is studying prostate cancer outcomes in African American and Caucasian populations.
- Richard Warnecke at the University of Illinois at Chicago is trying to understand the apparent disconnect between rates of screening and the stage at which breast cancer is diagnosed, as well as attempting to develop interventions that can manage breast cancer screening and prevention strategies at the community level.

Collectively, these researchers are looking at both upstream and downstream factors that affect health outcomes. They are considering factors such as social conditions and policies, institutions, neighborhoods, social relationships, individual risk factors, and biologic/genetic factors that may affect health disparities. Preliminary evidence from one of the centers suggests that social isolation leads to larger tumors in mice. Population studies have shown that gentrification of neighborhoods (which has been described as a form of social isolation) has resulted in 24% higher rates of tumor growth among lower-socioeconomic-status women. It is hoped that the RFA for this program will be reissued in approximately 1 year.

Despite the efforts of this program and other related programs, health disparities persist. Summit participants, particularly representatives from the community, should use the Summit as an opportunity to
suggest strategies to NCI and NCMHD as to how they should change their focus to better address cancer health disparities. It is vital that ongoing research and partnerships are critiqued so that people can come together more effectively to create good, sustainable programs with good partnerships.

**Community Networks Program**

*Kenneth Chu, Ph.D., Chief, Disparities Research Branch, CRCHD, NCI*

The Community Networks Program (CNP) began as the Leadership Initiative and became the Special Populations Networks (SPN) program in 2000 before transitioning to the CNP in 2004. The purpose of the Program is to reduce cancer disparities through community-based participatory education, research, and training. To achieve this, the goal of the Program is to significantly improve access to and utilization of beneficial medical cancer interventions.

The CNP consists of three phases. The first phase, Capacity Building and Education, extends through all 5 years of the Program (2005-2010). The Disparities Research and Training phase began in 2006 and will continue through 2010. The third phase, Establishing Credibility and Sustainability, will be a focus in the final 2 years of the program. The organizational structure of the CNP is similar to the structure of its predecessor, the Special Populations Networks, with the addition of a community advisory group and the inclusion of clinical partnerships. The addition of clinical partnerships to the existing community and research/training partnerships has allowed the CNP to study the health care delivery system as well as develop educational materials.

There are currently 25 CNP-funded programs, which are being supported by a total of $95 million over 5 years. There are seven national/multistate programs, nine regional/statewide programs, and nine local programs; 13 of the programs are former SPN grantees. The target populations of the various programs are as follows: eight African American; four Hispanic; four American Indian/Alaska Native; three Pacific Islander; two Asian; and four underserved.

During the Capacity Building and Education phase, sites establish their organizational infrastructure and begin to develop their partnerships. Partners include the community, screening clinics, hospitals, non-governmental groups, and others. The programs are also required to generate four collaborations with other NCI Centers, Divisions, and/or Offices. It is hoped that these collaborative relationships will help NCI realize how important community partners are for their work. The programs become involved with both primary (e.g., smoking cessation, hepatitis B vaccination) and secondary (cancer screening) prevention activities within the community.

A program evaluation has been built into the CNP from the beginning to monitor ongoing progress rather than wait until the end of the program. All 25 programs have submitted information about their first year’s activities and have transitioned to phase II. The first-year evaluation found that 339 people work on the staffs of the CNPs; 171 clinical partnerships have been created with screening clinics and hospitals; 641 partnerships have been created with community organizations, local/state governments, and nonprofit organizations; and 898 educational activities have taken place over the first year.

Phase II activities will include addressing a spectrum of research issues necessary to reduce disparities in the community; training researchers from minority/underserved populations in disparities research; and developing pilot projects to reduce cancer disparities. Fifty-one pilot project proposals have been submitted and are currently being reviewed.

The primary goal of phase III CNP activities is to reduce cancer disparities in the community. Because it will be impossible to observe decreases in mortality over the 5-year course of the project, alternative metrics to evaluate progress toward this goal have been adopted. These metrics include improved knowledge, attitudes, and perceptions about cancer; increased positive health behaviors (e.g., smoking
cessation, improved nutrition); and increased use of preventive and screening services. Programs should also be working to secure non-CRCHD funding to continue their community network activities.

**Key Points of Discussion**

**Overview of Participating Programs (Part I)**

- **Linkage of the Cancer Information Service with the National Library of Medicine.** The National Library of Medicine has developed and is developing specialized information service sites for disparity populations, including Alaska Natives, American Indians, Asian Americans, and African Americans. Currently, the CIS is not working with the National Library of Medicine on this effort. The only existing collaboration between CIS and the National Library of Medicine is focused on ensuring that the clinical trials in the PDQ database are also present on clinicaltrials.gov and that the information contained in the two databases is consistent.

- **Needs of the Poor and Uninsured.** Uninsured individuals who take advantage of free screening services and display a positive/abnormal result often do not have access to needed follow-up health care. The Cancer Information Service refers individuals in this situation to the CDC breast and cervical cancer screening program or to other resources, but this continues to be a huge issue. There are other NCI efforts under way to attempt to harness existing resources to help uninsured patients in this regard; for example, it may be possible to capitalize on the work that the Catholic community does with the uninsured and attempt to focus some of these resources on cancer.

  Researchers and community advocates can work to identify and link women with resources that are available at the local, regional, or national level. These individuals should make themselves aware of resources available through the CDC, the Patient Advocate Foundation, and other groups. They should also create links to community health centers.

  There should be a system developed by which university medical centers or other health care facilities can provide free oncology care to very poor people. Pediatric oncology should be used as a model—pediatric cancer patients can be given free care at any hospital in the country, largely because 90% of pediatric cancer patients are involved in clinical studies.

  Advocates should also participate in political lobbying to secure funding for follow-up care for diseases other than breast and cervical cancer.

- **Cancer Information Service Hours of Operation.** Currently, the CIS cancer information specialists are only available during normal business hours. Unfortunately, many people who would benefit from this service work during these hours and are thus unable to utilize it. CIS is in the process of performing a cost analysis to determine whether it has the flexibility to extend the hours to reach a broader audience.

- **Sustaining Programs.** It is often difficult to sustain effective community interventions after grant funding has expired.

- **Dissemination.** Cancer Control PLANET provides a good mechanism to disseminate information about evidence-based interventions as well as related tools and resources.
Overview of Participating Programs (Part II)

Moderator: Francisco Sy, Office of CBPR and Outreach, NCMHD

Overview of the Minority-Based Community Clinical Oncology Program

Worta McCaskill-Stevens, M.D., M.S., Division of Cancer Prevention, NCI

The Minority-Based Community Clinical Oncology Program (MBCCOP) was created within the Community Clinical Oncology Program in 1990 because the CCOP was not adequately accessing minority populations. The goals of the MBCCOP are to provide support for clinical research in communities with greater than 40% minorities; provide state-of-the-art treatment and cancer prevention and control; and increase the involvement of primary health care and other specialties in cancer prevention and control. There are currently 14 MBCCOPs, which are funded through the U10 mechanism. The initial funding period is for 3 years and competitive renewals can be funded for up to 5 years.

High overall interest in increasing minority participation in clinical research and an increase in applications to the MBCCOP prompted a recent evaluation of the Program to obtain a better understanding of the impact of clinical trials in reducing health care disparities. A previous evaluation was carried out approximately 10 years earlier. The goals of the 2004 evaluation were to evaluate trends in accrual; determine racial and ethnic distribution; and evaluate factors that affect enrollment. Data were gathered from the NCI CTEP and DCP databases as well as from the proceedings of a recent MBCCOP meeting and through an email survey. The email survey asked MBCCOP investigators to comment on the community advisory boards of their sites. Investigators provided information about the number and type of participating physicians in their programs and whether these physicians were enrolling patients or only referring them to clinical trials. The survey also collected information about the experiences of the MBCCOPs in involving minority physicians. Finally, MBCCOP investigators provided information on their publications and reported levels of support received by other oncologists within their institutions.

The accrual analysis looked at MBCCOP patient enrollment to both treatment and cancer prevention/control trials. Throughout the 1990s, accrual to cancer prevention/control trials was considerably lower than to treatment trials. The late 1990s saw increases in accrual to both types of trials. Between 1999 and 2001 the number of patients on treatment clinical trials through the MBCCOP more than doubled. MBCCOP enrollment in cancer prevention/control trials also began to increase in 1999; by 2003 the number of MBCCOP patients in prevention/control trials was more than double the number enrolled in treatment trials. This was in part due to the STAR and SELECT trials. Between 1995 and 1999, minorities comprised 51-60% of MBCCOP cancer prevention/control clinical trial enrollees; this climbed to 80% in 2003. A higher percentage of patients enrolled through MBCCOPs are minorities compared with patients enrolled through other CCOPs or non-CCOP avenues. Between 1995 and 2003, although MBCCOPs comprised only 20% of the CCOP network, MBCCOPs enrolled 33% of the minorities in CCOP treatment trials and 44% of the minorities in cancer prevention/control CCOP trials.

The 2004 MBCCOP evaluation identified a number of protocol-related issues and compared these with issues identified in the 1993 evaluation. Many issues that were cited in 1993, including patient ineligibility and comorbidities, persisted in 2004.

The survey also gauged institutional support. Although university support was identified as strong in 1993, sites surveyed in 2004 reported decreasing university support and a general lack of appreciation and understanding of MBCCOP research by administrators. Many sites found it necessary to seek increased assistance from pharmaceutical companies and local cancer centers to support their programs.

In 1993, fear, language barriers, attitudes, and education were some of the major barriers faced by MBCCOP patients. In 2004, significant in-migration of various populations resulted in increased gaps in
education, income, and health beliefs. These factors contributed to difficulties designing protocols that were language-appropriate for diverse populations and securing protocol-related drugs.

Major barriers reported by MBCCOP community physicians in 1993 were patient load, lack of incentives for participating in clinical trials, inadequate staff, and distrust. Some of these barriers persisted into 2004, but many sites made progress in these areas. The majority of sites reported strong commitments from their community physicians.

The MBCCOP also has the ability to mentor other sites that are interested in clinical trials. For example, a private practitioner in San Juan, Puerto Rico opted to participate in the SELECT trial. He accrued over 1,000 men and became overwhelmed with the time and regulatory demands of the trial. The San Juan MBCCOP stepped in and assisted him with data management, IRB access, and audit preparations.

The MBCCOP sites have contributed substantially to the scientific literature, publishing 46 manuscripts since the Program was initiated.

**Minority Institution/Cancer Center Partnership Program**

*Nelson Aguila, D.V.M., Program Director, Comprehensive Minority Biomedical Branch, NCI*

By 2050, the groups identified as medically underserved will comprise about 50% of the U.S. population; thus, there is a critical need to create programs that address issues in cancer health disparities.

The Minority Institution/Cancer Center Partnership (MI/CCP) program has four goals. The first is to build competitive research capabilities at minority-serving institutions, in part by increasing the number of investigators doing cancer research at these institutions; this is very important because these investigators often have the ability to do effective health disparities research. The second goal is to create stable, long-term collaborations between partner institutions in cancer research, training, education, and outreach. Thirdly, the program strives to improve the effectiveness of cancer center programs that benefit underserved minority populations. The final goal of the MI/CCP program is to export successful approaches and models.

MI/CCP partnerships must be based on equality and mutual benefit, qualities that must be demonstrated in the proposals. Although the grants are prepared collaboratively, each institution must submit its own application. The two grants are reviewed as one, given the same priority score, and, if funded, are funded as one project.

The MI/CCP program has used three funding approaches in the past—the P20, U56, and U54 mechanisms. Beginning in fiscal year 2007, the U56, or planning grant for a comprehensive minority/cancer center partnership, will not be available. The P20 is used to support Feasibility Studies for Collaborative Interaction between an MSI and a cancer center. This is a 4-year, nonrenewable mechanism with a total cost of up to $400,000 per year for both institutions. Projects must focus on one of the four MI/CCP target areas—research, training, education, or outreach. The grant supports administrative and development costs and can be used to fund pilot studies for up to 3 years with a budget of up to $120,000 for direct costs each year. All funded projects must result in a competitive grant proposal, and partnerships should illustrate other outcomes, such as joint publications, training of students, and outreach to the community.

The U54 partnership mechanism is a 5-year renewable grant funded through a cooperative agreement. These grants can have a budget of up to $2.5 million and must focus on research, training, and outreach. Educational activities are optional, although most partnerships have an education component. In addition to providing funds for pilot studies, the U54 MI/CCP grants support up to $275,000 of direct costs for full research projects or programs. Participation of investigators from the MSI and the cancer center are required in these studies.
The MI/CCP program has defined a number of expectations for its grantees. Over the first year of funding, investigators and institutions must demonstrate leadership, strategic planning, and effective communication between and within partner institutions. Programs supported through both mechanisms (P20 and U54) must have internal advisory committees to oversee the activities and progress of the partnerships. Programs supported by a U54 must also develop a Program Steering Committee, an external committee composed of up to six investigators from outside institutions that evaluates the partnership on an annual basis. There are also a number of intermediate and long-term expectations, including joint publications; grant funding; training and career development activities; matching and leveraging of funds; resource and infrastructure development; and service on committees.

More information on the MI/CCP program can be found at [http://minorityopportunities.nci.nih.gov](http://minorityopportunities.nci.nih.gov).

**Patient Navigation Research Program**

Roland Garcia, Ph.D., Center to Reduce Cancer Health Disparities, NCI

There are a number of different definitions of patient navigation, and patient navigators often perform functions at different parts of the screening-diagnosis-treatment-survivorship continuum. CRCHD is attempting to convince the community to adopt a consistent definition of patient navigation.

The NCI Patient Navigation Research Program (PNRP) is based on the hypothesis that patient navigation will help reduce and/or eliminate access barriers. It will do this by improving timely diagnosis following abnormal test results, timeliness and quality of treatment following positive diagnosis, and patient satisfaction with the health care system. It is also hoped that patient navigation will contribute to the cost-effectiveness of cancer care.

The research question at the center of the PNRP is: What are effective intervention strategies, from the point of abnormal cancer finding, to ensure equal access to quality, standard cancer care for all patients? There are a number of relevant research questions under this overarching question, including:

- What type of impact does the type of navigator have on navigation success? Does it matter whether navigators are paid or unpaid?
- Does the location of the navigator (i.e., outpatient or hospital based) impact outcome?
- What is the impact of the type of navigator (i.e., social worker, nurse, lay individual, community worker)?
- Does matching race/ethnicity or language improve outcome?
- Does the type of navigator affect cost-effectiveness?

The PNRP is designed to reach underserved populations. In addition to racial/ethnic minorities, this includes people of lower socioeconomic status, residents of rural areas, and members of other underserved populations. The Program defines patient navigators as trained, culturally competent health care providers who provide support and guidance to patients with abnormal findings in accessing timely cancer care and overcoming barriers to quality, standard care.

The PNRP recognizes that the primary care physician is the most important and consistent presence in the medical care of a patient and therefore formal arrangements between community health centers and hospitals are critical.

There are currently nine PNRP grantees. Eight of these are funded by NCI and the ninth is supported by the American Cancer Society. All of the sites must address breast, cervical, colorectal, or prostate cancer; two of the sites address all four.

ACS also funds a centralized, 3-day patient navigator training program. The first day provides an introduction to cancer and patient navigation. Day 2 presents background information about research,
culture and diversity, and communication. The third day is a practicum that involves role-playing to help navigators test and develop their skills in patient assessment as well as barrier and resource identification.

**Project EXPORT**

*Derrick Tabor, Ph.D., Program Official, NCMHD*

Similar to many of the other programs that have been presented, NCMHD supports research, community-based participatory research, institutional and community partnerships, capacity and infrastructure building, research training, and outreach. However, the Center does not focus on a single disease or condition, such as cancer. This is a good thing because most people who experience health disparities do not just have cancer; most are suffering from more than one disease and/or condition.

Project EXPORT (Excellence in Partnership, Outreach, Research, and Training) is one of the NCMHD programs designed to address minority health and health disparities. The partnership aspect of Project EXPORT is central. The program includes partnerships among and between research institutions, minority-serving institutions, tribal colleges, and others.

The NCMHD currently has two RFAs that seek to build on the capacity and infrastructure established during the first 4 years of the program. The new Center of Excellence program guidelines require only two cores—research and administration—rather than the original four; the training and community engagement cores are optional. This new system allows institutions greater flexibility.

The complexity of health disparities requires that investigators carefully integrate interdisciplinary expertise. Researchers having interest in biologic or social determinants contributing to health disparities must begin to work together to address health disparities, and the new Centers of Excellence program provides current NCMHD Project EXPORT grantees and new applicants to do so.

NCMHD and Project EXPORT are attempting to build sustainable programs so that the commitment to health disparities continues even after NCMHD funding ends. It is hoped that the bridge developed between the community, the institution, and the researchers is maintained over the long term.

Project EXPORT sites have successfully published manuscripts of their work, and it is anticipated that these publications will actually contribute to improving minority health and ultimately eliminating health disparities. These should be the metrics by which the success of health disparities research is judged.

**Key Points of Discussion**

**Overview of Participating Programs (Part II)**

- **Patient Navigation Research Program.** The PNRP currently does not provide substantial support for research that examines preclinical issues relevant to patient navigation (e.g., how decisions are made by individuals and families). The Program is working to standardize data elements so that all of its programs are collecting the same types of data. It is possible that one of these data elements will examine preference and whether traditional medicine has a role in this.

- **Needs of the Poor and Uninsured.** The M.D. Anderson Center for Research on Minority Health includes a health referral specialist in each of its research projects. This person is a social worker who helps patients understand their problems and find resources for which they might qualify.

  Another Houston-based organization, The Rose, has developed a physicians’ network for breast cancer treatment. Each of the medical professionals in this network agrees, if called upon, to treat at least one woman per year free of charge.

- **Lobbying for Funds.** Although Federal employees are prohibited from lobbying, private citizens and community leaders can encourage Congress to maintain and increase funds for programs that address
health disparities. Lobbying activities can address research in general or specific diseases or other types of research.

- **MI/CCP Options.** An individual from North Carolina Central University inquired about the possibility of applying for a U54 with two research partners and was advised to contact MI/CCP program staff.

**Profiles of Selected Best Practices within Disparate Communities: Putting Our Best Foot Forward (Part I)**

*Moderator: Jon Kerner, Ph.D., Deputy Director, Division of Cancer Control and Population Sciences, NCI*

**Profiles of Selected Best Practices within Disparate Communities: Putting Our Best Foot Forward**

*Jon Kerner, Ph.D., Deputy Director, Division of Cancer Control and Population Sciences, NCI*

It has been said that when dealing with cancer, our job is to comfort the afflicted. However, the job of the health disparities research community is to afflict the comfortable.

For many years, the NIH has operated under the idea that the creation of evidence-based knowledge through research should ultimately affect public health, but it has become clear that this knowledge must be actively transferred into routine or representative practice. Also, in addition to research influencing practice, practice should influence research. In this regard, research-practice partnerships need to be built and sustained.

NCI has adopted the Knowledge Integration Model. This Model calls for combining explicit knowledge from research with tacit practice and contextual knowledge. It is this integrated approach—with researchers and practitioners working together—that will ultimately help to address health disparities.

The NCI has issued three program announcements to support the study of how best to disseminate and implement evidence-based interventions into practice. More information on these program announcements and other NCI activities in this area is available at the Research Dissemination and Diffusion Web site: [http://cancercontrol.cancer.gov/d4d](http://cancercontrol.cancer.gov/d4d).

**Community Empowerment**

*Grace Ma, Ph.D., Director, Center for Asian Health, Temple University*

Asian Americans are one of the fastest growing populations in the United States and constitute the second largest foreign-born group. The majority of Asian Americans, 61%, speak an Asian language at home and many do not speak English well or at all, which complicates the health care delivery system. There are poverty issues among Asian Americans and many subsets of this group have very high rates of uninsurance.

Asian Americans experience the highest rates of liver and stomach cancer and have the third highest incidence rates of breast, lung, and colorectal cancer. Vietnamese women have the highest rate of cervical cancer and many Asian Americans are diagnosed at later stages of cancer than the general population.

In 2000, Temple University established the Center for Asian Health, one of the first efforts in the Nation designated to reduce cancer health disparities in Asian Americans. In the same year, the University also created the ATECAR (Asian Tobacco Education, Cancer Awareness, and Research) Network, which is supported through the NCI Special Populations Networks program, and the Asian Community Cancer Coalition (ACCC). In 2003, the New York site of the Center for Asian Health was established.
ATECAR is primarily targeted to the Chinese, Vietnamese, Korean, and Cambodian communities and other underserved Asian populations in the eastern region of the United States. The Network has developed seven strategic components: partnership building, outreach, research, training, dissemination, policy advocacy, and cancer health service delivery. The ultimate goal of the ATECAR Network is to reduce cancer health disparities through education, research, training, and early detection.

The Asian Community Cancer Coalition became the foundation of the ATECAR Network. Currently, there are 56 member organizations in the Network, including community organizations, churches, and community health centers. The ACCC serves as a community advisory board, identifying Asian community health needs and making recommendations for the Network. They also foster and participate in Asian community cancer and tobacco prevention and intervention activities through collaboration.

The Network has worked to identify critical cancer and tobacco problems in Asian communities and emphasize the importance of cancer control. They have also been working to help the community to understand the rights of research subjects, the issues associated with IRBs, and the importance of research data collection.

In 2000, the Network conducted a comprehensive needs assessment on tobacco and cancer awareness in Asian Americans in the region served by ATECAR. The community was involved throughout the entire process, including project planning, instrument development, recruitment, data collection, publication, and dissemination.

In 2005 and 2006, a similar approach was adopted to conduct a client baseline survey. Approximately 2,000 Asian Americans have been involved in this study, including Chinese, Koreans, Vietnamese, and Cambodians. The survey is examining issues related to cancer needs and cancer care as well as the barriers experienced by these populations. The preliminary data from this survey indicate that a large percentage of the Asian population have never had a general health checkup, mammogram, Pap smear screening, or colorectal cancer screening. In response to these data, the Network has established pilot interventions to address tobacco prevention and cessation as well as other health problems faced by the community.

The ATECAR Network has worked with the community through joint planning meetings during which the community and researchers work together to generate strategies and action plans. This has contributed to a strong trust relationship with the community and community leaders. The Network has adopted a community-based participatory research model that involves identification of community needs, intervention development, and evaluation.

ATECAR has also emphasized community capacity building and leadership. The Network has sponsored regular training programs for community leaders to empower them in making decisions about their organizations. It has also worked with the Cancer Information Service to integrate the program and its resources with the Asian communities. ATECAR is also trying to empower youth leadership. The ATECAR Network is working to improve the sustainability and self-reliance of the community and build community pride.

The Network is beginning to measure the outcomes of its community-based participatory research. Several of its pilot interventions have begun to deliver promising results. For example, there has been an increase in the percentage of Vietnamese women who receive cervical cancer screening. Hepatitis B/liver cancer screening has also increased, and the adult tobacco cessation program observed a large quit-rate at the 6-month follow-up.

In addition to publishing in many peer-reviewed, scientific journals, the Network has been involved in the publication of 150 newspaper articles, many in Asian-language periodicals.
Strategies to Increase Native American Investigators in Cancer Research: the Native American Cancer Research Partnership
Louise Canfield, Ph.D., Arizona Cancer Center

The Native American Cancer Research Partnership (NACRP) is a partnership between Northern Arizona University (NAU) and the Arizona Cancer Center (AZCC) dedicated to the alleviation of the unequal burden of cancer among Native Americans through the development of Native American cancer researchers and clinical oncology health care professionals. NACRP is founded on the core values of support, commitment, communication, and respect. Communication is key to integration of the diverse cultures in Tribal communities and the two Arizona universities. All NACRP programs are initiated and implemented in partnership with communities.

NACRP comprises three interlocking units; research, education/training, and outreach. The objective of the education/training component is to facilitate the entry of Native American students into careers in cancer research or clinical oncology. Students are recruited into programs at Northern Arizona University or the University of Arizona (UofA) tribal colleges/schools.

In developing courses to target Native American students it was discovered that materials appropriate for local Tribes were not available. Working in partnership with community members, programs were developed that empower students by incorporating culturally relevant materials in the curricula and including students in the design of curricula and research projects. The University of Arizona offers courses in Native knowledge and Western science, laboratory training, cancer biology for health care professionals, and a clinical shadowing program for undergraduates. A new master’s program in chemical carcinogenesis prepares NAU students to enter the graduate program in cancer biology at AZCC. In addition, students receive training and mentoring in the laboratories at NAU and AZCC.

To leverage resources, the Partnership has developed extensive networks at the two universities that include offices of Multicultural Affairs, Indigenous and American Indian Studies, and Native American student organizations at the two universities. The Departments of Chemistry at both universities have incorporated NACRP courses and programs into their curricula, most notably an undergraduate chemistry laboratory course at UofA and a master’s program at NAU. In addition, NACRP is a supporting member of ArizonaNativeNet, a virtual university outreach and distance learning telecommunications center based at the UofA College of Law devoted to the higher educational needs of Native Nations (http://www.arizonanativenet.com). Collaborative projects in progress include courses on cancer biology for community health care workers.

Student recruiting efforts primarily target tribal colleges and junior colleges and are accomplished in collaboration with Health STARS at NAU, http://home.nau.edu/msc/star/description.asp, and the First Year Scholars Program at the UofA, http://nasa.web.arizona.edu/scholarsprogram.html.

Since its inception in September 2002, over 90 Native American students have participated in NACRP programs. Thirty of these have now graduated and are either pursuing graduate degrees or are employed in oncology-related professions.

San Juan Minority-Based Community Clinical Oncology Program
Luis Baez Diaz, M.D., F.A.C.P, Principal Investigator, San Juan Community Clinical Oncology Program

Puerto Rico is an island between the Caribbean Sea and the North Atlantic Sea, which houses nearly 4 million inhabitants. There are between 11,000 and 12,000 new cases of cancer in Puerto Rico each year; the most common cancers for men and women are prostate and breast cancer, respectively.
The San Juan Minority-Based CCOP began as a collaboration between Dr. Baez and Dr. Ron Bloom at New York University in 1988. The program was officially funded as an MBCCOP in 1990 and initially worked with ECOG, M.D. Anderson Cancer Center, and the Fox Chase Cancer Center. Since then, it has also begun to work with the National Surgical Adjuvant Breast and Bowel Project, the University of Michigan Cancer Center, and the Moffitt Cancer Center. A segment of the partnership agreement allows for medical fellows to rotate at the partner institutions.

Initially, the MBCCOP sites in Puerto Rico were all within the medical center in San Juan; however, in 2000 the program expanded to include small community groups of oncologists to increase its catchment area. The program is planning to expand again in 2007 with the addition of the Bayamon Cancer Center.

Between June 1, 2005 and May 31, 2006, the MBCCOP accrued over 500 patients to cancer prevention/control trials; accrual for cancer treatment trials was 111.

The San Juan MBCCOP faces a number of challenges and barriers. The biggest challenge is dealing with IRB-related issues. For a period of time, the program was using four different IRBs and had to prepare both English and Spanish consent forms for all four of these Boards; the MBCCOP has since stopped working with one of these IRBs, but still bears a large burden in dealing with the requirements of the remaining three. For example, all of the IRBs originally required the Principal Investigator to be present at all IRB hearings, which was very time consuming. All but one of the IRBs now allows an associate or administrator for the trial to attend in place of the Principal Investigator.

One of the administrative barriers experienced by the MBCCOP is the need to design cost-neutral studies (i.e., the cost of the trial must be the same as the cost for standard care). Another significant barrier is the need to fund and support a pharmacy; NCI does not provide pharmacy support so this service must be supported by internal funds. Hospital charges are also not accounted for in the NCI grant. Some of the partner hospitals do not fully understand the nature of the MBCCOP support by NCI and mistakenly think that performing research is financially profitable.

The program has also encountered a number of physician barriers. Many of the participating oncologists thought that the clinical trial treatment paradigms were too toxic and wanted to be able to modify doses in order to avoid toxicity and additional hospitalizations. Physicians also needed to be educated to utilize the clinical trials as more than a late resource; many oncologists were not referring patients to trials until their disease stage was too advanced for inclusion on the protocol. Many physicians are also engaged in very busy practices and have difficulty finding the time to dedicate to enrolling patients on clinical trials. MBCCOP data managers and fellows often work with physicians to relieve at least part of this burden by helping the physicians perform evaluation, registration, and follow-up activities.

Puerto Rico health care reform has also impacted MBCCOP activities. The reform was instituted to provide care for the 1.5 million medically indigent Puerto Ricans who have no health insurance. This reform is directed to primary care and provides poor coverage for a number of treatments and services, including administration of growth factor. Private health insurance companies have also imposed problems for some protocols, particularly with limits on the number of imaging scans that are covered each year. The MBCCOP has attempted to circumvent this problem by focusing on trials that include less imaging.

Other barriers include a limited research base and fluctuating interest and support from NCI. Language poses another barrier for the MBCCOP. In this regard, it is important to note that the Spanish language used by Mexicans is not the same as the Spanish language used by Puerto Ricans; thus, written documents, such as consent forms, prepared for one Spanish-speaking population may not necessarily be appropriate for another Spanish-speaking population.
Cancer Health Disparities Summit: Communication Systems
Cherie Spencer, M.S., NCI Mid-Atlantic Cancer Information Service

The Cancer Information Service partnership program works closely with the Community Networks Program, the Patient Navigator Research Program, and the Minority-Based CCOPs.

Communication systems are very important for CIS because it is a national network of regional sites that also work closely with partners. It is very important that program updates and training curricula be shared easily between sites. Also, communication is essential for cross-regional collaborations such as the partnership between the Southeast and the Mid-Atlantic CIS centers that focuses on educating African American ministers about clinical trials in collaboration with the National Black Leadership Initiative on Cancer III. CIS is also collaborating with the Community Networks Program and the Southwest American Indian Collaborative Network to offer the latter a training program called Cancer 101, which provides background information on cancer to help plan community programs. This program was developed in the Northwest CIS region and has been disseminated to several partner groups.

Many CIS partnerships cross multiple time zones; for example, the Pacific CIS alone covers four time zones. The Pacific CIS is currently working with the Native Hawaiian Cancer Network and two area hospitals that are funded for patient navigator programs to develop patient navigator training curricula. The Rocky Mountain CIS region also covers a dispersed geographic area and utilizes conference calls and Webinars to coordinate activities across the region. Communications systems are also used by regional programs to convey strategic planning initiatives, training, and staff management issues to offsite staff.

CIS utilizes a number of different systems for Network-wide communications. The Partnership Portfolio Database includes information on all current projects and enables all Network participants to stay up to date. National meetings allow regional CIS staff to learn about different programs and curricula (e.g., Body and Soul, Using What Works) as well as identify ideas for how to disseminate evidence-based interventions. Other communication tools include Meet Me calls, program management calls, Webinars, and the listserv. Newsletters are also used to provide regular updates.

The mid-South CIS region recently worked with the Appalachia Cancer Control Network (ACCN) to provide a Cancer Control PLANET training Webinar. This was an effective way to provide training for 63 partners in 11 different states. One of the major goals of the meeting was to encourage partners to begin to utilize research-tested interventions and Cancer Control PLANET. ACCN will be tracking trainee use of Cancer Control PLANET and will assess its impact on their program planning.

Key Points of Discussion
Profiles of Selected Best Practices within Disparate Communities: Putting Our Best Foot Forward (Part I)

- **Alignment of Community and University Priorities.** Sometimes when communities become empowered, they realize that their goals and objectives do not necessarily coincide with those of the university or researchers. This is particularly relevant for immigrant populations whose highest priority is working to meet their daily needs. Dr. Ma reported that for her program, building a trust relationship with the community helped the community realize that the effort was benefiting them and resulted in improved community commitment.

- **Needs of the Poor and Uninsured.** The state of Delaware recently passed legislation under which the state provides full cancer care coverage for 1 year for all cancer patients whose incomes are up to 400% of the poverty rate, irrespective of their ability to pay. People in other states should contact their state government and point to Delaware as an example of what can be done to support cancer patients, particularly the poor and uninsured.
- Mixed Populations. Collaboration between researchers studying different racial/ethnic minority groups is important, but it is also important to address the needs of mixed populations, which are the fastest growing ethnic group.

Closing

Tarsha McCrae, M.P.H., Public Health Analyst, CRCHD, NCI

Ms. McCrae thanked the panelists for their participation in the Summit and reminded attendees to fill out and submit their evaluation forms for the first day of the meeting. She also encouraged everyone to attend the Grantee Poster and Resource Networking Session.

July 18, 2006

Opening Remarks

Derrick C. Tabor, Ph.D., Program Official, NCMHD

Dr. Tabor welcomed meeting participants to the second day of the Summit and encouraged them to introduce themselves and network with the people around them. He shared a quote from Chief Dan George to illustrate the need for institutions, researchers, and the community to communicate with one another and to work together—“If you talk to the animals, they will talk to you, and you will know each other. If you do not talk to them, you will not know them, and what you do not know, you will fear. What one fears, one destroys.” He encouraged participants to fill out evaluation forms for the second day of the meeting.

Profiles of Selected Best Practices within Disparate Communities: Putting Our Best Foot Forward (Part II)

Moderator: Peter Ogunbiyi, Ph.D., D.V.M., Program Director, Comprehensive Minority Biomedical Branch, NCI

Best Practices within Disparate Communities: Leveraging Project Resources

Electra Paskett, Ph.D., The Ohio State University

The Center for Population Health and Health Disparities (CPHHD) at The Ohio State University is called “Reducing Cervical Cancer in Appalachia.” The goal of the Center is to understand why Appalachian Ohio women have high incidence and mortality rates of breast cancer. The project covers 16 Appalachian Ohio counties, including both urban and rural counties. The Center supports three main projects and has four main cores.

The first project addresses cervical cancer screening among Appalachian populations. The goal of the project is to increase Pap smear screening. The project utilizes a lay health educator to deliver an educational intervention. The approach is currently being tested in a randomized trial.

The goal of the second project is to decrease tobacco use among adult Appalachian women. The project aims to characterize social, behavioral, and biologic factors related to tobacco use and test scientifically valid tobacco cessation interventions. Lay health advisors deliver the interventions.

The third project is examining variables that contribute to the increased risk of developing cervical abnormalities among Appalachian women. It is a case-control study in which HPV and cervical cancer smears are correlated with etiological factors to determine which are associated with abnormal findings.
The Center has a number of opportunities. Investigators are able to work in transdisciplinary teams as well as across all eight of the NCI-funded Centers for Population Health and Health Disparities. This allows the Center to explore issues across multiple levels. The Center is also able to fund other research ideas.

The investigators within the Center are using a conceptual model developed by investigators within the CPHHD initiative that describes how they view the health disparities they are studying. There are both upstream and downstream factors. They take into account biological pathways, individual characteristics, patterns of social organization, and the fundamental causes of health disparities, including social conditions and policies. The Center is unique because it considers each health disparity it studies at multiple levels of causation and potential intervention.

The Center also faces a number of challenges. The budget of the Center was cut 23% when it was first funded and, like many other programs, it has been subjected to cuts every year; this is coupled with the additional costs associated with doing community research. There are also methodological challenges in trying to balance the integrity of the research project with the needs of the community. The individual clinics also present their own issues; for example, one of the clinics is forced to close for weeks at a time each year during flood season.

The Center has found ways to leverage its resources to deal with many of the challenges it faces. University funds were used to buy equipment, such as freezers and centrifuges, for clinics in need. Donations from the nonprofit James Hospital were used to support extra personnel, which allows for increased recruitment of women to the studies. The hospital Development Office has also secured support from places like Abercrombie and Fitch and the Fraternal Order of the Eagles Women’s Auxiliary; the latter provided money to help read the Pap smears. Other institutional resources were also used to fund a CDC subcontract to analyze HPV specimens as well as personnel costs, equipment, and access to the general clinical research center.

The Center has also secured additional funding from a number of sources. It became a subcontractor of the University of Kentucky Appalachian Community Cancer Network. It was funded as the Ohio Patient Navigator Research Program. It also received a minority supplement to support one of its investigators, an Appalachian woman who is the first in her family to graduate from high school and college. The Center also worked with community coalitions to obtain additional funding. It received a grant through the local Komen Foundation and acquired funds from the Ohio American Cancer Society to fund a colorectal cancer initiative. In partnership with one of its community clinics, the Center has also submitted a grant to the Lance Armstrong Foundation to fund an Appalachian Center for Cancer Survivorship.

The Center supports a number of training opportunities. Public health students are able to incorporate the projects of the Center into their thesis work. There are also several junior faculty working in the Center. The Center has received one K award to date and is hoping that another will be funded soon. The Center has funded three pilot grants for junior investigators that will hopefully develop into R01 proposals. There are also numerous opportunities for students and junior faculty to author manuscripts.

Current funding levels cannot effectively reach underserved populations; therefore, creative strategies are needed to bridge the gap between need and reality. The Ohio State University Center for Population Health and Health Disparities has demonstrated that working with institutions to manage funded projects is one way to meet this need.
Program Sustainability

Mariano Rey, M.D., Institute for Community Health and Research, New York University School of Medicine

Three things are necessary to promote sustainability of a program—leveraging of resources, community health workers, and the community itself. Resources that need to be leveraged include the original grant, other government funds (e.g., state, local), and institutional funds. A good relationship with the community is crucial to the success of any community-based program.

The New York University Center for the Study of Asian American Health is a P60 Project EXPORT Center of Excellence. It is the only Project EXPORT Center that works exclusively with Asian Americans. The Center contains four cores—administration, outreach, training, and research. The research core houses four separate tracks—mental health, carcinogenesis/tumorigenesis, communication and culture, and 1-year pilot projects. The carcinogenesis research track focuses on tumors predominantly seen in Asian populations, such as nasopharyngeal cancer and lymphomas that result from Epstein-Barr infection. Studies are also being conducted on cervical, breast, prostate, lung, and colon cancer.

Several of the 1-year pilot projects have been able to secure outside grant support. One project, Project Aspire, was created to study the metabolic syndrome and severe cardiovascular disease in thin people, an observation that is seen predominantly in Filipino and Kurdish populations. Last year this project received an 11-year health disparities grant to look at the prevalence of hypertension and cardiovascular disease in Filipinos. A second project, the Asian American Hepatitis B Program, has received funding from the New York City Council and New York State. A total of $8 million has been received from various sources, and the Program has now screened 4,000 people in a year and a half. Private foundation money has also been attracted to support initiatives with the Southeast Asian community and the South Asian community.

The Center for the Study of Asian American Health held a community forum at the Filipino embassy mission in New York City in order to do a community health needs assessment. The information gathered through this forum was used as the basis for the grant application to the NIH for this community-based participatory research project. The program is completely dependent on community health workers and has a community advisory board.

The structure adopted by the Center for various projects includes an Executive Planning Committee that includes principal investigators and members of the community. There are also a number of task forces assigned to perform a number of different jobs, such as capacity building or needs assessment. Finally, these task forces interact with the community health workers who interface with the community.

Involving the community at every step is essential. The community needs to be involved in outreach, and programs should use the community to outreach to itself. The needs assessment process should also be performed with input from the community. Partnerships and relationships with the community need to be built before grant money is secured.

Collaborations/Partnerships: UPMC McKeesport

Dwight E. Heron, M.D., Cancer Disparities Research Partnership Program, University of Pittsburgh Medical Center McKeesport Hospital

The Cancer Disparities Research Partnership grants operate under a “bottom-up” approach rather than in the traditional “top-down” manner. Instead of having academic medical centers bring services or research projects to the community, the CDRP program allows the community to lead the process. NCI recognizes that the ideal mentors for this program are premiere academic centers that are nationally known in the field of radiation oncology. The community hospitals, such as UPMC McKeesport, also partner with local agencies that have well-established links to the community.
The UPMC McKeesport CDRP grant supports a network of five community hospitals spanning four health systems. The group receives mentorship from Washington University in St. Louis and the Roswell Park Memorial Cancer Institute. The program is also mentored locally by the University of Pittsburgh as well as the West Penn Allegheny Health System.

The McKeesport-based group engages in monthly TELESYNERGY® sessions with its primary mentor, Washington University, to discuss professional development. Quarterly TELESYNERGY® sessions with Roswell Park Memorial Cancer Institute are held to discuss clinical trials issues.

Although the official NCI name of the group is the Radiation Oncology Community Outreach Group, it was decided that a better name was needed to interface with the community. The name “Neighborhood Cancer Care Cooperative” was adopted for this purpose.

The program has a number of community partners and interacts with them in diverse ways to reach the community. Through partnership with the Center for Healthy Hearts and Souls, the program has distributed healthy lifestyle education handouts at 626 events and reached over 30,000 attendees. The Consumer Health Coalition works closely with patient navigators and assists in identifying coverage for uninsured patients. The local American Cancer Society also works closely with patient navigators to resolve prescription coverage and transportation barriers. The Pennsylvania Department of Health has served as a liaison to assist program staff in reaching the Amish community. The Lawrence County Cancer Coalition conducts health fairs/screenings and helps with networking and information sharing.

Program members are also actively involved in staffing a number of community agencies such as the Center for Healthy Aging, the McKeesport State Health Improvement Plan, and the African American Cancer Care Partnership. The African American Cancer Care Partnership, a new community partner of the program initiated by the University of Pittsburgh Medical Center and University of Pittsburgh Cancer Institute, is a $750,000 fund that will pay for the initial consultation for patients diagnosed with breast, colorectal, lung, or prostate cancer at one of the four designated UPMC sites. During this consultation, patients are evaluated for clinical trials eligibility. The Partnership has been in place only 3 months, and 8 of the 38 patients (21%) who have been served are entering clinical trials.

Sustainability is a crucial part of these community partnerships. If the programs begin to have an impact on health disparities but then disappear when the grant funding expires, nothing is accomplished. Some additional local partners are being explored by the UPMC McKeesport program, including the Equitable Resource Foundation and the G. C. Murphy Foundation.

**Key Points of Discussion**

*Profiles of Selected Best Practices within Disparate Communities: Putting Our Best Foot Forward (Part II)*

- **The African American Cancer Care Partnership.** This fund was created by the University of Pittsburgh Medical Center exclusively from the profits of the health system. The administrative leadership of the health system recognized a need in this area, prompting them to establish this fund for consultation. The program guarantees coverage of the initial consultation visit. It does not cover treatment, but the services provided through the program attempt to link patients with other resources for which they may be eligible, such as Medicare or Medicaid. Although recruitment to clinical trials is high through this program (25% to date), patients are not coerced into trial participation. All patients, regardless of ethnicity, are informed about clinical trials during the consultation process. The Partnership program is not designed specifically to get African Americans onto clinical trials.

- **Evaluation of Programs.** Effectiveness of programs and interventions can be measured in a variety of ways. A reduction in cancer incidence or mortality is the ultimate outcome, but it will often take a long time to see these kinds of results. Other metrics can be used to illustrate the impact of an intervention, such as the number of screenings or Pap smears received by the target population in an
intervention versus control group. These measurements often look at barriers that have been overcome (i.e., access to care). Other metrics include grants awarded, publications, and training of students and junior faculty. Securing funds from a host institution or other sources is another sign of success. Publications help disseminate information to the health care community but also to the communities that experience health disparities.

- **Publishing Health Disparities Research.** It often takes time to develop community-based research before manuscripts can be generated for submission to respectable journals. This timeframe is often daunting for master’s and Ph.D. students, but students often have the opportunity to plug into a project midway through and be part of the publication process. The current generation of students has the opportunity to benefit greatly from established mentors in the field of health disparities.

**Capturing Emerging Technologies**

*Moderator: Kaytura Felix-Aaron, M.D., Bureau of Primary Health Care, Health Resources and Services Administration*

**Introduction**

*Kaytura Felix-Aaron, M.D., Bureau of Primary Health Care, Health Resources and Services Administration*

Disparities, including cancer disparities, pose an interesting dilemma for technology. Left unchecked, the fruits of technology are often constrained by the social and economic arrangements of society, and reduction of disparities does not necessarily flow from technological advancements.

A recent study examined the use of eight diagnostic and therapeutic cardiac technologies in a health plan. It was discovered that blacks were less likely than nonblacks to receive exercise stress tests, radionucleotide stress tests, exercise cardiography, and cardiac stents. The study also found that differences in use varied by the duration of the technology; as a technology was widely disseminated and adopted, the disparities often increased, while disparities decreased as use of a technology generally declined.

The promise of emerging technologies to reduce and eliminate disparities will depend on the research and delivery communities thinking carefully through the discovery-development-delivery continuum.

**caBIG: From Pilot to Enterprise—Connecting the Cancer Community**

*Ken Buetow, Ph.D., Director, NCI Center for Bioinformatics*

The goal of caBIG (the Cancer Biomedical Informatics Grid) is to create a virtual web that connects the entire cancer community, accelerating discovery and bringing new treatments to patients more quickly. It is based on the premise that information is power and recognizes that in order to enable patient-centered molecular medicine, information from all communities must be brought together. caBIG will only succeed with the active engagement of the entire cancer enterprise, including all stakeholders. All voices, all faces, and all communities should be part of this activity.

caBIG is a collection of communities—the clinical trials research community, the basic science community, the tissue bank and pathology communities, the *in vivo* imaging community, and technical communities that support the development of a common language and common infrastructure. Also necessary is a community that supports data sharing, training, and strategic partnerships.

The caBIG community is intensely focused on developing, testing, and delivering products. The goal is to provide tools to support the entire cancer enterprise—from basic science discovery to delivery of care and patient support—through an open-source, open-access, open-development framework. There is a steady
move towards interoperability; existing tools are retrofitted and new systems are created to be caBIG compatible.

The caBIG community is attempting to build an infrastructure that will link together the patient care, regulatory, and clinical research worlds. This is being done through the creation of an open infrastructure that supports activity throughout all of these worlds and promotes the sharing of all information associated with the clinical enterprise.

It is recognized that there are many challenges to broadly disseminating caBIG tools to all of the communities in the cancer enterprise. There are physical barriers for some communities who are not electronically connected. Also, some tools are not culturally or ethnically sensitive to the different perspectives of diverse communities. This makes it critically important that the health disparities community is involved throughout this process.

The electronic nature of the caBIG effort has the potential to rise above common barriers because bits and bytes are value neutral with respect to race, color, creed, or geographic origin. This can be facilitated by engaging and empowering navigators and trusted community leaders with the infrastructure needed to support caBIG activities.

One of the activities supported by caBIG is the caMatch program, which is a Web portal that supports the development of personal health records. This infrastructure supports the integration of individual health records with the clinical research enterprise. It could conceivably allow health disparities communities to surpass some of the structural barriers to clinical trials involvement and become connected with the broader clinical trials enterprise.

The strength of the cancer enterprise is in its diversity. Different sectors are united in mission with an interest in solving critical problems. caBIG attempts to connect these sectors using state-of-the-art information technology infrastructure.

**Technologies to Enable Molecular Oncology**

*Gregory Downing, D.O., Ph.D., Director, Office of Technology and Industrial Relations, NCI*

Many applications of technology have the potential to both disrupt current health care systems and level health disparities. On the other hand, many of these platforms have the potential to create new kinds of health disparities that have not yet been considered.

The mission of the Center for Strategic Science and Technology Initiatives (CSSI) is to

- Foster development of innovative tools and technologies that enable discovery research and enhance delivery of clinical interventions for cancer.
- Integrate biology and technology to invent platforms for cancer detection, diagnosis, treatment, and prevention.
- Accelerate progress by supporting research infrastructure, common resources, and training.
- Promote dissemination through public and private-sector collaborations, communications, and entrepreneurship.

The emergence and convergence of technologies has enabled a shift from empirical testing of interventions to an approach that is targeted at specific genes and proteins.

The CSSI supports a number of programs that contribute to this shift. The Alliance for Nanotechnology utilizes platforms for detection and early diagnosis of cancer as well as monitoring of therapies. It is working to create multicomponent capabilities to target therapies using a number of different materials. There are several community outreach activities regarding nanotechnology. Public engagement and understanding are essential for driving these advancements to fruition. Proteomic technologies provide...
the ability to measure disease-associated proteins in patient samples using mass spectrometry or other \textit{in vitro} techniques. The Cancer Genome Atlas project is working in partnership with the National Human Genome Research Institute to identify genes relevant to cancer; those involved in this effort have been working to ensure that potential issues regarding health disparities are addressed and that new disparities are not created on the basis of how cancer genes are studied. The Office of Biorepositories and Biospecimen Research has been created to develop the necessary resources and science to support the collection of specimens from cancer patients. The newly integrated small business program is committed to using Institute funds to target activities related to the commercialization of technologies and other products. All of these programs are linked through caBIG.

The programs of CSSI are unique because they share budgets, materials, and infrastructure. The Center has developed multidisciplinary teams and collaborations with both academia and the private sector. Evaluations based on established milestones are carried out at both program and project levels to ensure that goals are being reached.

The Center is engaged in a number of partnerships. A joint effort with the National Science Foundation supports training programs for undergraduates in physical/chemical as well as life sciences to study the applications of nanotechnology. This program has been successful in recruiting minority investigators and helping to develop career paths for them. Other partnerships have been developed with the Departments of Defense and Energy, the National Institute of Science and Technology, and the Food and Drug Administration.

The technologies developed by CSSI and others create new opportunities for understanding health; determining how these technologies are best deployed and utilized for the benefit of all will require public discussion and the engagement of many communities.

\textbf{Key Points of Discussion}

\textbf{Capturing Emerging Technologies}

\begin{itemize}
  \item \textit{Preventing Discrimination}. There is concern that personal information identified and/or stored with emerging technologies could be used against individuals, perhaps affecting their ability to secure health insurance or employment. The Genetic Discrimination Act somewhat addresses this issue by making it illegal to utilize genomic information to make decisions about health insurance coverage or employment; the Act was passed by the Senate in March 2005 and is currently in Subcommittees in the House of Representatives. However, many technology-related issues are not addressed by this legislation. As technologies are developed, the capacity to protect human subjects must be integrated into them. The Federal Government is currently working in a variety of contexts to ensure that these protections exist and that access to information is controlled.

  \item \textit{Cancer Tissue Repositories}. The NCI has been working to develop repositories so that tissue specimens are available to investigators. First-generation guidelines on biobanking and biorepository practices have recently been developed to encourage uniformity in the way tissues are collected and shared. Human subjects protection is also addressed in these guidelines. There is need for standardized protocols so that information generated in different locations can be compared. Dr. Carolyn Compton leads the office that is dealing with these issues and her team has developed a number of approaches to ensure that different populations are equally represented in tissue collections.

  \item \textit{Dissemination of Technology}. There is concern that emerging technologies will not diffuse evenly to different populations unless steps are taken to address this issue. One important approach to this issue is to ensure that populations appreciate the benefits of technology and are not fearful of its implications. This type of education is best begun at early ages. Another way to empower different population groups is through partnering programs, such as those ongoing in the health disparities
research community. These partnerships can play a role in ensuring that communities have access to and understand these technologies.

Also, many of these technologies will produce information that is available to everyone so all members of the research community can benefit from it. For example, although not generated by all members of the community, the human genome sequence is available to all and broadly supports many aspects of biomedical research.

Communities and health care workers in the field should work to embrace the capabilities of these technologies rather than view them as obstacles.

The Influence of Health Disparities Research on Health Policy
Moderator: Claudia Baquet, M.D., M.P.H., Professor of Medicine and Associate Dean of Policy and Planning, University of Maryland

Policies are activities or strategies developed to achieve anticipated outcomes. In the case of health policy, the activities are expected to affect the health care delivery system or the recipients of health care. Policy may affect access to care, target scarce resources, or guide funding decisions. It may be implemented through legislation and/or regulation.

Health disparities research can contribute to health policy in a number of ways. It can document/describe the existence of health disparities and contribute to the understanding of the etiology of health disparities. Research has the ability to inform and guide the agendas of policymakers and can assist in defining the nature and extent of health disparities. The development of science-guided policy to reduce or eliminate health disparities can be heavily influenced by research. Research can also be used to evaluate policies to determine whether the desired outcomes have been achieved. Finally, when linked with policy, health disparities research can promote sustainability.

Health disparities research findings have successfully informed policy development in Maryland. This has been achieved through ongoing legislative technical assistance and clear demonstration of the needs of the constituency. Committee briefings, testimony at hearings, and workshops have also contributed to this success.

The Maryland General Assembly is composed of 188 Senators and Delegates. The Assembly meets in session for approximately 90 days and annually considers roughly 2,300 bills as well as the state budget. While the Assembly has the power to cut the state budget, the ability to increase the budget is reserved for the governor. Laws passed by the Assembly have the potential to affect the general welfare, create new executive agencies, and impose new taxes. A number of recent pieces of legislation in Maryland have been relevant to health disparities, including the cigarette restitution fund.

In 2001, the Maryland Center for Health Disparities worked with members of the General Assembly on House Bill 1425, the Cigarette Restitution Fund (CRF). This Bill resulted in significant funding for the community as well as for public health departments and academic institutions in order to eliminate cancer and other tobacco-related diseases. The Cigarette Restitution Fund supports a number of programs, including the University of Maryland Statewide Health. This is a community and telemedicine videoconference infrastructure comprising a number of community outreach centers throughout the state.

Other health disparities legislation includes the Health Care Disparities Prevention Act, the establishment of the Office of Minority Health and Health Disparities, and the creation of a health disparities policy.
report card. All three of these pieces of legislation have been sponsored by Delegate Shirley Nathan-Pulliam.

Mandated benefits legislation provides another example of the connection between research and policy. Mandated health benefits are required health insurance benefits or services that insured health plans must include. Maryland has approximately 40 mandates; unfortunately, these do not apply to the small-group market, including Medicaid or the self-insured. This means that approximately 75% of the population under the age of 65 is not covered by these mandates. Many of the underserved do not necessarily benefit from this legislation.

Mandates illustrate the connection between research and policy. Policy research was used to identify evidence-based treatments or procedures; legislative policy was developed around this research to assure access by mandated benefits. However, legislation is not always required—Medicaid and state employee benefits policies adopted mandates through regulatory change. In 2004, the University of Maryland School of Medicine conducted a focus group that indicated a general lack of awareness regarding these mandates, particularly in minority and rural underserved populations. Based on this, it was decided that interventions were needed to increase awareness of available benefits. A P60 grant from NCMMHD supported the development of an educational tool to explain mandated benefits to the most underserved communities in Maryland. The tool was tested by a focus group in Baltimore City in June 2006. Results of this focus group will guide revision of the educational tool and inform legislators about the understanding of legislated benefits by minorities and the underserved. This has the potential to lead to future policy changes.

The Southern Legislative Conference is composed of 16 rural states, including Maryland. The Rural and Agricultural Committee of the Conference is headed by a Maryland Senator who is a former tobacco farmer. He invited the University of Maryland group to present to the 16 states about ways they could organize their own policy and health disparities research. As part of this effort, a toolkit for state legislators was developed to guide them in replicating some of the successes that have taken place in Maryland.

In summary, health disparities research is a powerful tool for providing evidence for policy formulation, providing ongoing technical assistance to elected officials, assuring that policies are responsive to data, and fostering new policy research.

The Influence of Health Disparities Research on Health Policy: A Policymaker’s Perspective

Delegate Shirley Nathan-Pulliam, R.N., B.S.N., M.A.S., 10th Legislative District, Baltimore County, Maryland

Delegate Nathan-Pulliam reported that she enjoys educating her colleagues in the General Assembly about health disparities issues. Her involvement in instituting policies to combat health disparities has been sparked by observations and research findings that have been made over the past century. W.E.B DuBois and Booker T. Washington noted differences in health care for Negroes immediately post slavery. The Task Force commissioned by Margaret Heckler published numerous findings on black and minority health. In 2002, the Institute of Medicine released a report entitled, Unequal Treatment: Racial Inequities – Confronting Racial and Ethnic Disparities. The fact that information about health disparities has been available for so long and disparities still exist indicates that this issue needs continued attention.

Irrespective of age, gender, education, income, insurance, socioeconomic status, place of residence, and marital status, the health outcomes of African Americans and other racial/ethnic minorities are significantly worse than those of their white counterparts. This trend continues even when rates are standardized for genetic predisposition, severity of illness, and access to health care. It cannot be assumed
that everyone is aware of these data and statistics. Many people, even physicians and nurses, do not know this information.

Several institutions have been helpful in the process of crafting policy to combat health care disparities in Maryland. These include the HHS, the National Office of Minority Health, and the Maryland Office of Minority Health and Health Disparities; academic centers; industry initiatives; employer benefits purchasing groups; advocacy groups; and professional organizations. Academic centers that have been particularly involved are the University of Maryland School of Medicine, the Johns Hopkins School of Public Health and School of Nursing, and the Morgan State University School of Public Health.

Policymakers are able to develop new legislation that creates offices and task forces; initiates studies; and directs resources to certain programs. They are also able to modify existing legislation and convene meetings to encourage collaboration. Through public-speaking opportunities, policymakers are also able to raise public awareness about issues of interest.

The Cigarette Restitution Fund Program has been a model for health-disparities-related policy in Maryland. Through the CRF Program in fiscal year 2007, $9,950,090 has been devoted to cancer screening and treatment; $10,400,000 has been dedicated to cancer research; $3,000,000 has gone to support the statewide health network; $1,202,989 has been used for minority outreach grants; and $1,281,669 has supported surveillance and evaluation.

In order to achieve success, health disparities programs must embrace a comprehensive approach that is sustained over time and integrated into standard practice. Health disparities research projects should take place in real-time patient settings that reflect the challenges that affect provider-patient interactions. Also, health disparities research projects should require funded partnerships with local, federally qualified health centers; local health departments; local minority groups; and other community groups that form the existing network of providers. Funded partnerships with local hospitals and minority groups should also be required in order to spread new knowledge/best practices to wide geographic areas and establish credibility with minority populations that are difficult to reach.

Health disparities research needs to study/evaluate the impact of research funding to identify the outcomes and benefits to different population groups. Research findings need to be effectively translated to affect the lives of individuals and families in the community. Health disparities research must also define the economic impact of health disparities on Federal and state budgets as well as the economic benefit of reducing health disparities. Research should have a more direct impact on health policy at the Federal, state, and local levels. Finally, there needs to be better partnership among Federal agencies.

Those interested in health disparities can help their elected officials/policymakers in a number of ways. They should ensure that policymakers are educated about health care disparities. This can be accomplished in a number of ways, including inviting them to attend conferences and sending them written information. It is important to build collaborative relationships with legislators. It is also possible to become informal advisors or information sources for policymakers, helping them review language in bills and providing comments and suggestions. Providing testimony at bill hearings may also be of benefit.

In the 12 years since she was elected to the General Assembly, Delegate Nathan-Pulliam has sponsored at least 40 pieces of legislation, many related to health care access and quality that have become law. Some of these include the Health Disparities Prevention Act and establishment in 2004 of the Maryland Office of Minority Health and Health Care Disparities. This Office holds public health forums; collects and analyzes data; develops a strategic plan; and provides grants to community-based organizations.

In 1998, Delegate Nathan-Pulliam was the primary sponsor of legislation for a Breast Cancer Treatment Program, which provided $2.6 million each year for breast cancer treatment for low-income women.
Another bill passed into law provided $500,000 each year for oral cancer, which disproportionately affects African American males. Over the past year, Delegate Nathan-Pulliam introduced six pieces of legislation on health disparities, four of which passed. One of these, the Racial and Ethnic Variation bill, requires the Maryland Health Care Commission and the Office of Minority Health and Health Disparities to work together to collect racial/ethnic data.

Using Research and Finding Synergies: A Tale of Two Conditions

Nina Bickell, M.D., M.P.H., Project EXPORT Center of Excellence, Mount Sinai School of Medicine

The Mount Sinai EXPORT Center is in East Harlem and interacts with the neighborhoods in both East and Central Harlem. Harlem borders the Upper East Side, one of the most affluent neighborhoods in New York City; however, both East and Central Harlem have a much higher disease burden than the Upper East Side. There has been an apparent reduction in health disparities as Harlem has become gentrified, but this is likely because the disparities populations are moving to other places.

The Center operates under the hypothesis that underuse of effective care is more prevalent in minority populations and may be an important cause of health disparities. The Center is working to intervene to remedy underuse and reduce disparities. The paradigm used by the Center begins with identifying a precise definition of underuse. This is followed by a measurement of underuse rates and an assessment of the causes of underuse examined by race and ethnicity. This assessment allows the development of tailored interventions, which are then implemented within the community. Finally, the impact of these interventions is measured.

Researchers must keep in mind the fiscal realities currently faced by hospitals and how these relate to the implementation of effective interventions. If hospitals enhance their outpatient management and improve the health of their patient populations, costs are borne by the hospital. A reduction in hospitalizations and emergency department visits results in decreased hospital revenues. This means that if hospitals adopt effective interventions, they will be paying for the interventions as well as experiencing reduced revenues.

The Mount Sinai EXPORT Center focuses on two conditions—early-stage breast cancer and congestive heart failure. These conditions share a number of properties. They are both prevalent and associated with a huge burden of suffering. Effective treatments exist for both conditions; however, these treatments are often underused.

The breast cancer project is supported by the Project EXPORT P60 as well as funds from the Agency for Healthcare Research and Quality. It is known that there are effective adjuvant treatments that improve disease-free and overall survival for early-stage breast cancer. It is also known that these treatments are underused. When the Center examined treatment patterns in six different New York City Hospitals, it found that women from all racial/ethnic groups were getting diagnosed with stage I and II breast cancers and that these women were undergoing treatment for their cancer. This indicates that these women successfully accessed care; however, whether the women went on to receive effective adjuvant care following surgery (e.g., chemotherapy, radiation, hormone therapy) depended on their racial/ethnic group: 1 in 3 black women and 1 in 4 Hispanic women did not receive effective adjuvant treatment compared with only 1 in 6 white women. One factor that appeared to be protective was referral to a medical oncologist.

One-third of the cases of underuse were found to be due to system failures. System failure describes the situation in which a physician recommends treatment and, although the patient does not refuse it, she fails to receive the treatment. To determine the reasons behind these system failures, Center researchers found that not a single physician’s office, regardless of the affluence of the area it served, had a systematic way to track the care it recommended to its patients that would be given by another physician. This means that
there are no systems in place to track whether patients connect with oncologists to whom they are referred. The Center has developed a tracking system to target this failure and will be testing it in a clinical trial.

Congestive heart failure is another large burden on society for which effective treatments are available, but underused. Patient interviews indicated that patients were not very knowledgeable about their disease conditions. To address this, a nurse management intervention was culturally tailored for East Harlem. One component of the intervention involved patient education about dietary salt, daily weight measurements, medications, and the importance of follow-up. Medication dosages were optimized through a nurse management strategy and phone calls were used to follow up with patients. All of these activities were done in a randomized fashion. The evaluation showed that the intervention improved physical functioning while physical functioning of the usual-care group declined. Hospitalizations were also reduced. Unfortunately, not a single hospital adopted this program at the end of the study.

At around the same time, the Alliance for Health Improvement was created through a partnership of the Mount Sinai and North General Hospitals. The Alliance is a limited liability corporation created as part of the conversion of hospital outpatient clinics to diagnostic treatment centers. The Alliance uses the increased reimbursements it gets for diagnostic treatment functions to support the implementation of evidence-based research protocols into their clinical service delivery. It then assesses the effects of these interventions.

Identifying synergies and strategizing about the choice of conditions and effective interventions to implement are key ingredients for success when working to combat health disparities. These must be coupled with strong leadership that is willing to invest in improving the quality of care. The challenge is that these commitments cost money and hospitals are bearing the cost while states and managed care organizations realize the savings. This results in a misalignment of incentives for hospitals that are trying to improve quality and reduce disparities. Legislators should consider ways in which different reimbursement models can promote implementation of effective health interventions.

**Key Points of Discussion**

*The Influence of Health Disparities Research on Health Policy*

- **Challenges in Educating Policymakers.** Legislators in some states are subject to term limits. This can be frustrating for groups trying to educate their policymakers about health disparities, because just as delegates become knowledgeable about the issue, they are forced to leave office. In this situation it is important to begin educating and working with potential representatives even before they are elected and then continue the process after they are in office. It would also be useful to create mechanisms through which legislators, including new legislators, are continually educated about the issue.

Another potential approach is to hold town hall meetings with representatives to discuss issues related to health disparities. Representatives could be asked to inform their constituents about how they have voted on related issues in the past.

- **National Policy.** Individuals and groups interested in targeting health disparities through policy should also target Congress. Solutions can be created through policy work at multiple levels—local, state, and Federal.

- **Mount Sinai EXPORT Center.** The community has been actively involved in the work of the Center from the outset. The community advisory board was actually in place before the grant was written and the community has provided input on the conditions about which it is concerned. The Center has created community newsletters to which academic and community representatives contribute articles. The Center has also been working to train individuals within different community organizations to become peer educators in chronic disease self-management. This kind of approach ensures that expertise exists within each of the organizations and will continue beyond the grant funding cycle.
Charge to Breakouts

_Derrick Tabor, Ph.D., Program Official, NCMHD_

_Jamelle Banks, M.P.H., Office of Science Planning and Assessment, NCI_

Ms. Banks described the objectives for the breakout sessions:

- Promote and sustain cancer health disparities programs during times of increasing budget cuts.
- Maximize existing resources through strengthened collaborations.
- Generate recommendations for NCI/NCMHD, healthcare professionals and researchers, and the community.

Each of the seven concurrent breakout sessions would focus on one of the following topics:

- Managing and sustaining programs
- Collaborations/partnerships
- Communication systems
- Community engagement
- Accrual strategies
- Training
- Health policy.

Each breakout group would have two facilitators—one Federal and one non-Federal. A professional writer would be present to capture the discussion. Participants would be expected to contribute their ideas, experiences, and recommendations. The facilitators would work with the writers to generate presentations that would be reported back to the larger group on Wednesday, after which an opportunity would be provided for everyone to provide input.

The results of these breakout sessions will be a substantial portion of the product generated from the Summit. This comprehensive report will be given to the NCI Director and will outline for him the impact of flat/decreasing budgets on health disparities programs and the ability of these programs to work with communities.

**July 19, 2006**

Remarks and Administrative Notes

_Nadarajen Vydelingum, Ph.D., Deputy Director, CRCHD, NCI_

Dr. Vydelingum welcomed the participants to the third and final day of the Summit and expressed his excitement about the community programs that have been initiated and continued over the past year. He encouraged the group to engage in active dialogue regarding the observations and recommendations of the various breakout groups. This discussion will be incorporated into the Summit report, which will be used by NCI and NCMHD as they develop plans and initiatives for the future. Dr. Vydelingum also asked participants to fill out the evaluation forms to help the individuals who plan the Summit make the meeting even better in years to come.
Discussing Funding Opportunities with Federal Agency and Foundation Partners

**Moderator:** Lisa Evans, J.D., Senior Advisor for Policy, NCMHD

**Discussing Opportunities with Federal Agency and Foundation Funding Partners**

*Helen Lettlow, Dr.P.H., Associate Vice President for Priority Populations, American Legacy Foundation*

The American Legacy Foundation (Legacy) supports a number of programs designed to reduce tobacco use and dependence among priority populations (i.e., racial/ethnic minorities, low-income populations, rural populations, gay/lesbian populations). In the past 3 years, Legacy has awarded $21 million in grants in this area.

The Foundation does not exclusively fund research but does provide funding for research-related pilot projects, particularly for community collaborations, academic-community partnerships, and state and local health departments. While these funds are generally much smaller than Government grants, they do provide an opportunity to accumulate data that can be later used to support larger research grant applications.

Legacy’s Priority Populations Initiative (PPI), just one component of the Foundation’s grants program, represents its commitment to support grassroots efforts aimed at reducing tobacco’s deadly toll in priority populations. PPI funds a number of projects across the Nation.

The Tobacco Research in Practice Settings (TRIPS) grant is operated by the Morgan State University Drug Abuse Research program in collaboration with the Maryland State Department of Health. It was developed to increase the number of African American tobacco researchers within and beyond Morgan State University. Through the program, university students and faculty are able to work with epidemiologists and other public health professionals to collect and analyze data and write research reports for publication.

The Native American Indian Center of Central Ohio (NAICCO) is also funded by PPI. This initiative is led by a group of public and private partners and addresses the high rate of tobacco use among Native Americans in Central Ohio. Native American populations in Ohio and across the Nation have the highest prevalence of tobacco use among all racial/ethnic groups.

Legacy also funds the LGBT Incubation Project at Fenway Institute in Boston. This project built upon information gleaned from think tanks of lesbian, gay, bisexual, and transgender leaders to create an innovative tobacco cessation model for these communities. The model expands upon previous research into social support by simultaneously recruiting groups of friends into a cessation program that is guided by a psychologist. This project is currently being prepared for publication.

Roswell Park has been performing a smoking cessation study among Medicaid populations in Buffalo, New York. The project compared the cost-effectiveness of three different counseling methods designed to promote the use of Medicaid-covered pharmacotherapy to quit smoking. Methods included in-person counseling; written information on the Medicaid benefit and cessation literature; or written information on the Medicaid benefit alone. Cessation attempt and success rates and associated costs were tracked for 3 months. Preliminary data suggest that a number of Medicaid patients were not even aware that Medicaid covers pharmacotherapy and a number of other related counseling services.

The New York Chinese American Tobacco Control Initiative (NY-CATCI) is housed in the Charles B. Wang Community Center in New York City. This project is designed to reduce tobacco use among New York-based Chinese American youth. It also aims to increase the number of Chinese American homes that ban smoking and increase the successful smoking quit rate among Chinese Americans.
The TReND program is jointly funded by Legacy and the National Cancer Institute. The program was developed out of the need to stimulate research that would help identify and eliminate tobacco-related health disparities across the tobacco continuum (i.e., from tobacco use and exposure to tobacco-related cancers). The mission of the program is to eliminate tobacco-related health disparities through transdisciplinary research that advances science, translates scientific knowledge into practice, and informs public policy. One of the projects funded through the TReND program—African Americans, SES, and Smoking—focuses on the heterogeneity among African Americans regarding the natural history of tobacco use and explores the role of socioeconomic status in tobacco use across the lifespan. Another project, the Small Sample Size Population Project, is exploring ways to develop reliable estimates from small sample size groups. A third project aims to examine approaches to the measurement of socioeconomic status and considers what these measurements should include in the 21st century. The TReND program also supported a health disparities research methods training workshop to increase the competency of researchers in this area, promote the use of innovative methods, and create opportunities for collaboration. Another TReND-funded project involves a recent special edition of the journal Addiction.

The American Legacy Foundation is committed to providing $2.1 million over 3 years for projects in the following three areas:

- Developing innovative community-level interventions that integrate smoking cessation into health promotion programs.
- Addressing the dual challenge of tobacco use and underage drinking or substance abuse.
- Reducing secondhand smoke exposure through the use of in-home smoking bans utilizing faith-based approaches to health promotion.

More information on these initiatives can be found at www.americanlegacy.org or by e-mailing Dr. Lettlow at hlettlow@americanlegacy.org.

**Bridging the Gap: CDMRP Health Disparity Initiative**

Barbara Terry-Koroma, Ph.D., Minority and Underserved Populations Program Manager, Congressionally Directed Medical Research Programs

The Congressionally Directed Medical Research Programs (CDMRP) came about as the result of grassroots efforts in the breast cancer community. Breast cancer advocates lobbied Congress and secured a $210 million appropriation for breast cancer research, which was added to the Department of Defense (DoD) budget. Since that time additional programs focused on different diseases have been added, including the Prostate Cancer Research Program (PCRP) and the Ovarian Cancer Research Program (OCRP). Approximately $127.5 million, $80 million, and $10 million are spent on the breast, prostate, and ovarian cancer programs, respectively, each year.

The CDMRP is a series of partnerships between Congress, the DoD, consumer advocates, and scientists and clinicians. Consumer advocates sit on all CDMRP panels and contribute to decisions about which proposals should be funded.

Disparities in breast and prostate cancer have been well documented. Although SEER data do not reveal clear disparities in ovarian cancer, disparities are thought to exist in some locations and among some groups of women.

To begin addressing health disparities, the CDMRP established the Minority and Underserved (MIU) Populations Program in 1998 (originally called the Special Populations Program). The creation of this program was informed by the Minority Health Initiative; the Initiative brought scientists and clinicians doing disparities research as well as representatives from various ethnic communities together to advise
the DoD on the best direction for the Program. In accordance with the recommendations of the Initiative, the MIU Populations Program solicits proposals from disease-disparity-focused researchers and investigators at minority-serving institutions.

A number of funding mechanisms focused on health disparities have been created and adopted by the various CDMRP disease programs. The Prostate Cancer Program is very committed to disparities because of the high incidence and mortality rates for prostate cancer among African American men. The PCRP developed the first of the CDMRP grants to address minorities—the Minority Population Focused Collaborative Training Award. The PCRP also sponsors a number of other grants targeting disparities. The HBCU Collaborative Partnership is designed to support clinical trials at the medical schools of Historically Black Colleges and Universities (HBCUs). Other grants are available to support health disparity research and training at all types of institutions. The Collaborative Undergraduate HBCU/MI Student Summer Training Award provides the opportunity for students from minority-serving institutions to perform summer research projects at institutions that focus on prostate cancer research.

The Breast Cancer Research Program (BCRP) sponsors the HBCU/MI Partnership Training Award to support trainees at all types of minority-serving institutions. The Ovarian Cancer Research Program supports a similar award for research—the HBCU/MI Collaborative Research Award.

The PCRP has funded a number of different projects related to prostate cancer disparities. Several of these grants have focused on the genetic basis of disparities and have examined things such as mutations, gene expression, and environmental effects. The PCRP recently awarded $10 million to a project examining the influences of health care, cost, and tumor biology on racial differences in prostate cancer. Factors included in the analysis are genetics, diet, socioeconomic status, and access to health care. One of the focuses of the project is the difference in prostate cancer incidence between African American men in New Orleans and Chapel Hill, North Carolina. African American men in New Orleans display the lowest incidence of prostate cancer in the country while those in Chapel Hill have the highest rates. A number of the New Orleans patients were lost to follow-up in the aftermath of Hurricane Katrina but efforts have been made to recruit additional patients from parishes that were less impacted by the storm.

More information on the CDMRP can be found at [http://cdmrp.army.mil](http://cdmrp.army.mil).

**American Cancer Society Research and Training**

*William Phelps, Ph.D., Scientific Program Director, American Cancer Society*

The American Cancer Society was founded in 1913 as the American Society for the Control of Cancer. The name was changed to American Cancer Society in the mid-1940s. The Society’s research program was established in 1946. Mary Lasker and her friends raised $4 million and used $1 million of that money to start both extramural and intramural research programs. Since that time, ACS has invested some $2.8 billion in cancer research. ACS dedicates more money to cancer research than any other private, nonprofit, nongovernmental agency in the United States.

The ACS research budget for 2004-2005 was approximately $125 million. This is about 3% of the NCI budget of $4.8 billion and includes funds for both the intramural and extramural programs.

Several years ago the Society decided to focus the majority of funding on new investigators in order to foster the best and brightest scientists at the beginning of their careers; approximately 80% of ACS extramural funding supports this effort. ACS is also committed to a balanced portfolio that contains basic, clinical, preclinical, and applied research in addition to some training. Approximately 7 years ago, the Society made a commitment to create a research program to specifically encourage research on poor and medically underserved populations. All of the research initiatives of ACS are overseen by the so-called Blue Ribbon Committee, which is an external committee that meets every 5 years to evaluate and recommend changes to the ACS research program.
Three of the major ACS extramural funding mechanisms are the Postdoctoral Fellowship Program, the Mentored Research Scholars Grant, and the traditional Research Scholar Grant. The Postdoctoral Fellowship Program is for fellows within 3 to 5 years of having completed their terminal degree (M.D. or Ph.D.). The duration of the grant is up to 3 years and it allows for a stipend of $40,000 to $44,000 per year. ACS funds 60 to 70 of these each year, which consumes about 9% of its budget.

The Mentored Research Scholar Grant is a transitional award intended for junior faculty, particularly those focused on clinical and applied research. Investigators qualify for these awards in the first 4 years of their independent appointment and can receive up to 5 years of funding. ACS funds 10 to 15 of these each year, which accounts for approximately 5% of its budget.

The Research Scholar Grants are for independent investigators within 6 years of their first independent appointment. Up to 4 years of funding is provided with up to $200,000 per year in direct costs plus 20% indirect costs. The Society funds about 100 of these each year and these grants account for about 70% of its budget.

ACS supports a broad range of research, including projects in the areas of prevention, detection, and treatment as well as psychosocial and behavioral, health policy, and health services research. ACS also provides a little over $2 million each year for training grants to train professionals in oncology, including primary care physicians, social workers, and nurses.

Since 1999, 10% of the Society’s extramural research budget has been dedicated to poor and medically underserved populations. This has included support for over 60 applications for a total of more than $51 million. These projects have focused on diverse areas from behavioral and health policy research to more basic science. Approximately one-third of these studies have focused on African Americans, with additional studies on Hispanic and Asian populations.

Numerous investigators and projects have been funded to study cancer in poor and medically underserved populations:

- Sharon Graw at the University of Denver has identified an unexpectedly high frequency of the 185delAG BRCA1 mutation in Hispanic breast cancer patients with ancestry in the San Luis Valley of Colorado/New Mexico.
- Manuela Orjuela at Columbia University is investigating the role of folate deficiency in poor children in the development of sporadic retinoblastoma.
- Christopher Weghorst at The Ohio State University is studying chemoprevention of oral cancer in Appalachia.
- Katrina Armstrong at the University of Pennsylvania is examining distrust as a barrier to cancer screening and prevention among African American, Caucasian, and Hispanic women.
- Suzanne Christopher at Montana State University is developing culturally sensitive programs and partnerships to improve cancer screening and Pap screening in Apsaalooke Indians.
- Lovell Jones at the M.D. Anderson Cancer Center is working on the African American Women’s Nutrition for Life project.

ACS has recently issued an RFA in the field of health policy research entitled “The role of healthcare and insurance in improving outcomes in cancer prevention, early detection, and treatment.” The purpose of this RFA is to stimulate research on the effects of the U.S. healthcare system structure and the role of insurance in determining access to screening and treatment. The program is specifically interested in the effect of disparities in health care in prevention, early detection, and quality treatment. The letter of intent for this program was due by August 15, 2006, and the application deadline was October 15, 2006. Approximately $1 million has been set aside for this program, which will be run through the Research Scholar Grant program.
**Key Points of Discussion**

**Discussing Funding Opportunities with Federal Agency and Foundation Partners**

- **Engaging Partners in Research.** A few years ago the Director of the Office of Civil Rights, who was interested in racial/ethnic data collection, generated a letter to several health insurance providers co-signed by then-Surgeon General David Satcher. The letter outlined the importance of collecting racial/ethnic data and informed the providers that they were not precluded by law from collecting such data. As the result of the letter, several collaborations were initiated, pilot programs were created, and many health insurance carriers began collecting data on the race and ethnicity of their enrollees.

- **CDMRP Programs.** The HBCU Collaborative Partnership mechanism is designed to provide support for HBCUs that are doing research but need support to strengthen their programs and/or create a more independent research program. Through this grant, the HBCU receives the bulk of the funds; the collaborating institution can get a maximum of 25% of the award. The best candidates for these awards are HBCUs that have an existing relationship with another institution. The Breast and Ovarian Cancer Research Program grants are similar, except one is focused on research and the other on training.

- **Definition of “Minority Researcher.”** The CDMRP is prohibited from targeting any specific ethnic group, but the program does cover disease disparities of all ethnic groups. This includes African Americans, Hispanics, Native Americas, and Pacific Islanders.

  Similarly, the American Legacy Foundation does not have a formal definition for “minority researcher.” The Foundation focuses on health disparities populations and one of the priority populations is the broad category of Asian/Pacific Islanders.

  The American Cancer Society focus on poor and medically underserved populations does not include a racial/ethnic description or definition. The applicant simply needs to explain why its target group is a medically underserved population.

- **Prostate Cancer as an ACS Priority.** One of the meeting participants voiced concern that prostate cancer is not an ACS priority, specifically in the state of Florida. ACS funds research and activities in a number of areas, including prostate cancer, but is unable to meet all the needs of the community. There should be nationally run screening programs for prostate cancer, including some in the Florida ACS division. Divisional representatives would need to be contacted for more information on this matter.

**Reports and Recommendations from Breakout Sessions**

*Moderators: Derrick Tabor, Ph.D., Program Official, NCMHD*

*Jamelle Banks, M.P.H., Office of Science Planning and Assessment, NCI*

**Managing and Sustaining Programs**

*Facilitators: Pebbles Fagan, Ph.D., Division of Cancer Control and Population Sciences, NCI*

*Rae Mei-Ling Isaacs, M.P.H., ‘Imi Hale – Native Hawaiian Cancer Network*

**Priority Statement:** Develop a core process to ensure program continuity and identify and secure reliable resources to meet program obligations.

Identified priorities:

- Cross-fertilize programs in different disease areas (e.g., through a database of resources).

- Rethink the way health disparities are packaged and marketed.
Develop a partnership culture to reduce competitions and share resources.

How can/do you promote and sustain cancer health disparities programs during times of increasing budget cuts?

- Create partnerships with public and private entities.
- Leverage existing resources.
- Break programs down into discrete components that can be funded individually.
- Prevent cuts to community-based health disparities programs.
- Hold elected officials’ “feet to the fire.”
- Go beyond Federal funding.
- Demonstrate program efficacy to the mother institution.
- Create bridges between land grant and private universities so students can obtain higher degrees more cheaply through application for a cooperative agreement.

What resources, support, and/or infrastructure are available or needed to help you manage and sustain your cancer health disparities program?

- Piggybacking on existing resources and community funding.
- Sharing staff with other entities.
- Collapsing meetings to reduce meeting fatigue.
- Looking for additional resources for sustainability at the start of the program.
- Partnering with an entity that has high name recognition.
- Disseminating existing resources that provide technical assistance or a means to connect with other organizations.

How can/do you maximize and leverage existing resources through strengthened collaborations?

- Utilize Memoranda of Agreement (MOA) to formalize commitment and support.
- Exchange expertise and engage in co-learning among academic and community partners.
- Increase awareness of available funding opportunities.
- Increase collaboration among Federal agencies for grant opportunities to integrate disease categories.
- Educate communities to seek their own funding.
- Encourage collaboration among community groups (e.g., pool resources and money, reduce replication).

What types of management strategies can/have you develop(ed) and implement(ed) to help secure funding from non-NCI/NCMHD sources?

- Engage multiple stakeholders with shared values and create new themes to address health disparities.
- Utilize existing relationships with State Offices of Minority Health.
- Get involved in state cancer plans.
- Change the language of health disparities to “health equity” and “social justice” as a marketing strategy.
- Work more closely with university Development Offices.
Develop business plans to show businesses how health status affects their indicators (absenteeism, wellness).

What methods have you implemented to effectively manage funds and personnel during these times of flat and decreased budgets?

- Invest in staff training.
- Seek support from the mother institution (e.g., equipment, supplies, full-time employees).
- Utilize tobacco settlement money.
- Share FTEs, space, and resources with other departments, agencies, etc.
- Access surplus equipment and supplies from Government and university entities.
- Get involved with local banks, which must respond to the Community Reinvestment Act.

How do you develop and cultivate institutional commitment as part of your program's infrastructure?

- Utilize MOA and Memoranda of Understanding (MOU) to formalize relationships.
- Ensure that MOA/MOU do not create additional barriers.
- Include stakeholders on decision-making boards.
- Link program goals to institutional goals.

What recommended actions do you have for the following groups to help you manage and sustain your cancer health disparities programs:

- **NCI/NCMHD**
  - Provide opportunities to meet with other community networks during meeting time.
  - Create a central catalogue of all cancer health disparities projects for the purpose of sharing.
  - Issue a funded mandate for cancer centers to incorporate health disparities into their work.
  - Have realistic and clear expectations for program outcomes.

- **Healthcare Professionals/Researchers**
  - Make research outcomes accessible to the community.

- **Community**
  - Become familiar with the Freedom of Information Act so that community programs are accountable.

**Collaborations/Partnerships**

*Facilitators: Mona Fouad, M.D., J.D., University of Alabama at Birmingham*

*Valerie Maholmes, National Institute of Child Health and Human Development*

**Priority Statement:** Establish effective and mutually beneficial collaborations and partnerships among cancer centers, academic institutions, community-based organizations, Federal agencies, students, and community members with the common goal of reducing cancer health disparities.

How can/do you use collaborations and partnerships to promote and sustain your cancer health disparities programs during times of increasing budget cuts?

- Be creative and ask for needed resources.
- Form long-term partnerships that extend beyond a single grant.
Recognize the importance of NCI infrastructure and resources in creating infrastructure to attract other funds to sustain programs.

Create a culture of partnerships; the job cannot be done without collaborations and partnerships.

Work with coalitions to share information and pool services.

Use community and rural health research centers, radio stations, schools, health care agencies, universities, DOD, HRSA, etc., to provide health care access.

What resources, support, and/or infrastructure are available or needed to help you collaborate and partner with other organizations/communities?

- A rich, extensive partnership data resource (i.e., know what partners can offer).
- Partnering relationships that are transparent and equitable.
- Inclusion of disparities in the curriculum for health care professionals.
- NIH funds to facilitate leveraging of other partnerships and promote and foster the conduct of research.
- Resources that include access to basic research tools (e.g., libraries, manuals).
- Centers for community partnerships that provide a locus of expertise for brokering, supporting, and sustaining partnerships.

How can/do you maximize and leverage existing resources through strengthened collaborations/partnerships?

- Build partnerships that extend beyond a single project through endorsing, branding, and co-opting.
- Build capacity of partners (e.g., community-based organizations).
- Engage the business community.
- Keep open channels of communication with existing partners and bring in additional partners.
- Sustain relationships to meet the unique needs of partners; identify the vision and mission of partners.
- Encourage faculty to cross-train to bring in more resources and apply for funding from varied sources.

What types of collaborations/partnerships can/have you establish(ed) to help secure funding from non-NCI/NCMHD sources?

- Include insurance companies, the Department of Defense, policy-making groups, and the media.
- Involve an economist to help demonstrate the cost benefits of reducing disparities.
- Develop professional expertise to communicate across disciplines.

How have collaborations/partnerships been instrumental in facilitating and furthering your program activities?

- Increasing credibility.
- Supplying equipment and material.
- Sustaining programs that continue beyond the life of a grant.
- Establishing “Rules of Engagement” for community partnerships.
- Developing cancer education awareness through primary care providers.
- Partnering with mass media to take advantage of their expertise to get out the message.
What recommended actions do you have for the following groups to help you establish effective and mutually beneficial collaborations/partnerships between cancer centers, researchers, students, and community members that will promote and sustain your cancer health disparities programs?

- **NCI/NCMHD**
  - Increase networking opportunities by holding more meetings like the Cancer Health Disparities Summit, and consider involving a wider community.
  - Establish health disparities as a discipline.
  - Hold cancer centers accountable for the quality of the partnerships they establish.
  - Elevate health disparities in the scientific and policy-making communities.

- **Healthcare Professionals/Researchers**
  - Encourage minority scientists to become independent investigators.
  - Train minority leaders and administrators about the importance of research.

- **Other**
  - Include health disparities as a performance criterion in health care systems.

**Key Points of Discussion**

**Collaborations/Partnerships**

- **Creative Partnerships.** Groups should consider partnering with law schools, particularly with respect to health policy issues. These potential partners need to be invited to meetings such as the Summit so they can learn more about health disparities and let the health disparities research community know what they have to offer.

**Communication Systems**

*Facilitators: Kip Gallion, M.A., Baylor College of Medicine
Taylor Harden, Ph.D., National Institute on Aging*

*Priority Statement: Share communication tools, resources, and processes within and across programs, institutions, and all levels of the community that have been instrumental in facilitating program activities.*

*How can/do you use communication systems to help promote and sustain your cancer health disparities programs during times of increasing budget cuts?*

- Utilize media advocacy.
- Link with planned, special programming events on TV to highlight health disparities programs (e.g., Breast & Prostate Cancer Awareness Month, Black History Month).
- Use prepared “media kits” to keep messages fresh and disseminate them to the community.
- Involve the community in all phases of the program.
- Promote the program to decision makers (i.e., Congress, NCI/funders, project officers).
- Increase communication among community partners.

*What resources, support, and/or infrastructure are available or needed to help you share communication tools, resources, and processes within and across programs, institutions, and all levels of the community?*

- A searchable repository of communication resources, including:
- Research instruments for special populations
- Technical reports not available in PubMed
- Directory of centers, programs, and experts.

- Infrastructure for online meetings of communication groups.
- Language translation services.
- Media production/marketing services.
- Detailed information on all audiences.

**How can/do strengthened collaborations help you to maximize and leverage existing communication tools and resources?**

- Reaching underserved audiences and ESL groups (Latino and Asian subgroups).
- Providing clear health disparities messages via non-English-speaking TV and radio outlets.
- Co-branding products, cross-promoting programs, and bundling partner services.
- Supporting project-related communication tools (e.g., Web sites) after initial research funding has ended.

**What types of communication systems can/have you share(d) to help secure funding from non-NCI/NCMHD sources?**

- Sharing media channels with different content providers.
- Utilizing grant writing.
- Influencing the academic development office to identify local corporate support.

**What communication systems have been instrumental in facilitating and furthering your program activities?**

- Collaborating within and among community partners.
- Collaborating across CBPR centers.
- Conducting needs assessment with community partners.
- Developing coalitions and partnerships through interpersonal communications (not just electronic communication).
- Cross-promoting programs through different media.

**What recommended actions do you have for the following groups to help you share effective communication systems that will promote and sustain your cancer health disparities programs?**

- **NCI/NCMHD**
  - Make information about communications available in a central repository.
  - Increase collaboration among NCI-funded programs in close geographical proximity.
  - Enhance specialized resources (e.g., listservs of experts, Cancer Control PLANET).
  - Facilitate alternative opportunities for publishing communications-focused manuscripts.
  - Require communication plan components in all RFAs.
  - Create internship/fellowship/training opportunities for lay community partners and members of CBPR programs.
  - Create a community advisory task force on communication.
- Healthcare Professionals/Researchers
  - Facilitate collaboration among in-state and regional centers.
  - Facilitate project-focused collaborations (e.g., R13 conference grant application).
  - Develop online communities around themes/interests in health disparities.
  - Improve health literacy, cultural competence, and cancer communication skills.
  - Engage family gatekeepers (e.g., mother, wife) to disseminate health care messages to the entire family.
  - Participate in all phases of community life.
- Community
  - Take ownership of communication tools and strategies.

**Community Engagement**

*Facilitators: Vickie Shavers, Ph.D., Division of Cancer Control and Population Sciences, NCI*  
*Yosselyn Rodriguez, Latin American Cancer Research Coalition*

**Priority Statement:** Engage community members to assume greater leadership in addressing cancer health disparities.

*How can/do you actively engage the community to help promote and sustain your cancer health disparities programs during times of increasing budget cuts?*

- Overcome distrust:
  - Become a long-term partner.
  - Engage indigenous leadership.
  - Operate on their time.
  - Help the community to identify needs and stay with them.
  - Go to the community to give, not just to ask.
  - Agree on a definition of “partnership.”
- Focus on community assets; culture is not a barrier.
- Understand that immigration status cannot be a barrier; cancer affects all human beings.

*What resources, support, and/or infrastructure are available or needed to help you engage the community to assume greater leadership to address cancer health disparities?*

- **Time:**
  - Turnaround on RFA (it takes considerable time to engage the community).
  - Timing of release of RFA (summer/holidays are difficult times to engage the community).
- **Academic award paradigm** (look at how many people are helped, not number of publications).
- **Staff** who can cross boundaries and talk to the community and to researchers.
- Increased money and cap for pilots.
How can/do strengthened collaborations help you to actively engage community members to assume greater leadership in addressing cancer health disparities?

- Establish recognition of communities as co-owners of Community Networks Programs, not just entities “slotted in” to the researchers’ agenda.
- Establish community-based IRBs.
- Allow researchers to assist in the community on projects unrelated to their work.
- Provide technical assistance and health presentations in the community.
- Subcontract between universities and local resources to provide technical assistance (this builds their capacity).

How do/have you actively engage(d) the community to help secure funding from non-NCI/NCMHD sources?

- Building community capacity through training and awarding “mini-grants.”
- Utilizing a joint grant-writing process.
- Looking at local funding sources.

How has community engagement been instrumental in facilitating and furthering your program activities?

- Allow minority researchers to be principal investigators on CNP pilot projects.
- Focus not only on developing junior faculty, but developing community partners as researchers, too.
- Identify a mechanism to fund follow-up care.
- Recognize the need for funding to support best practices.
- Keep partners in the loop, even on budget cuts; they may have ideas.
- Develop community members as health promoters.
- Provide funding for chronic disease rather than specific disease.

What recommended actions do you have for the following groups to help you engage community members so that your cancer health disparities program is promoted and sustained?

- **NCI/NCMHD**
  - Commit to supporting community-based participatory research:
    - Extend timelines for RFPs and grants (11 years is a good timeline).
    - Evaluate partnerships to ensure community control and benefits.
    - Provide flexible budgets.
  - Utilize community conferences.
  - Allow programs to include and serve “undocumented” Americans; it will cost more to “treat” late-stage cancer than to include all in early detection programs.

- **Healthcare Professionals/Researchers**
  - Build community capacity.
  - Report findings.
  - Recognize that health professionals need to listen, care, and share more.
  - Develop medical school courses and CME programs in cultural competence.
Community

- Remind researchers that the community is the solution.
- Make more demands.
- Understand issues and challenges facing principal investigators.

Key Points of Discussion
Community Engagement

- Immigrants and Undocumented Residents. The needs and rights of all people, including immigrants and undocumented residents of the United States, need to be recognized because all people get cancer.

Accrual Strategies

Facilitators: Ted Trimble, M.D., M.P.H., Cancer Therapy Evaluation Program, National Cancer Institute
Ronda Henry-Tillman, M.D., University of Arkansas for Medical Sciences

Priority Statement: Implement culturally competent approaches to educate and recruit disparate populations to clinical and prevention trials/studies.

How can/do you use accrual strategies to help promote and sustain your cancer health disparities programs?

- Use general cancer education to highlight the importance of clinical trials.
- Gain community trust for cancer research.
- Emphasize early identification of eligible patients.

What resources, support, and/or infrastructure are available or needed to help you effectively educate and accrue disparate populations to clinical and prevention trials/studies?

- NCI Clinical Trials Education Series materials.
- Financial support for clinical trials infrastructure.
- NCI mandate for accrual of the medically underserved.

How can/do strengthened collaborations help you to maximize and leverage existing accrual strategies to educate and recruit disparate populations?

- Work with funded health disparities programs as well as other city, state, and Federal programs to ensure access to care.
- Utilize patient navigators.

What types of collaborations can/have you establish(ed) to help secure funding from non-NCI/NCMHD sources?

- Other Federal, state, and local programs.
- Foundations and charities.

What recommended actions do you have for the following groups to help you educate and increase recruitment of disparate populations to clinical and prevention trials/studies so that your cancer health disparities program is promoted and sustained?

- NCI/NCMHD
- Work with partners to ensure access to care.
- Work to ensure access to clinical trials.

Healthcare Professionals/Researchers
- Work with the community to increase education and trust.
- Promote cultural competency among health care professionals.
- Demonstrate a commitment to holistic health care.

Community
- Promote optimal cancer care.
- Promote clinical trials.

Key Points of Discussion

Accrual Strategies

Clinical Trial Accrual as a Health Disparities Issue. The question was raised whether clinical trials accrual of minority populations is a health disparities issue or addresses health disparities. In response, it was stated that accrual of diverse populations (e.g., genetic background, environmental exposures, cultural exposures) to clinical trials is necessary to determine whether interventions are effective in general or only more narrowly defined populations. Because clinical trials should be designed to meet the needs of all populations, minority accrual to clinical trials is viewed as an appropriate consideration in health disparities missions.

Ethical Issues Regarding Medically Underserved Participants in Clinical Trials. Patients, particularly those from medically underserved populations, should be assured optimal health care for all health needs when participating in clinical trials. The current U.S. health care system and clinical trials enterprise do not ensure that participants continue to receive care when a trial is completed.

Clinical Research Priorities. The cancer clinical trials enterprise should make a commitment to researching the two cancer sites with the worst overall survival—pancreatic cancer and liver cancer. Both of these sites are also associated with huge disparities; African Americans have high rates of pancreatic cancer and Asian Americans have the highest rates of liver cancer. A concerted effort should be made to recruit every patient onto clinical trials, similar to what has been done in the pediatric oncology community. Every patient should have the opportunity to be involved and benefit from clinical research in these areas.

Rural Populations. Programs need to be developed to ensure that rural populations have access to clinical trials.

Prevention Trials. Issues with accrual to prevention trials also need to be considered. These are very different from treatment trials and are associated with different barriers to accrual.
Training

Facilitators: Diane Rowley, M.D., M.P.H., Morehouse College
Michael Sesma, Ph.D., National Institute of Mental Health

Priority Statement: Address challenges and enhance strategies to increasing the recruitment, retention, and promotion of minority and underserved investigators in cancer health disparities research.

Successful Approaches to Recruitment, Retention, and Promotion of Minority and Underserved Investigators in Cancer Health Disparities Research:

- Internships.
- Curriculum development.
- Collaborative interdisciplinary training (social workers, nurses).
- Collaboration across diseases with similar risk factors.
- Collaboration with professional societies.
- Community engagement in the research process.

Barriers to Increasing Recruitment, Retention, and Promotion of Minority and Underserved Investigators in Cancer Health Disparities Research (Needs):

- Lack of mentors, especially from underrepresented populations, for investigators from underrepresented populations.
- Lack of culturally appropriate training for mentors and principal investigators.
- Inadequate faculty development at MSIs.
- Inability to provide students with a structured, funded pathway to guide them through their education and into a career in academic research.

Recommended Actions to Help Recruit, Retain, and Promote Minority and Underserved Researchers to Promote and Sustain Cancer Health Disparities Programs:

- NCI/NCMHD
  - Effectively utilize training/career development grants:
    - Designate a portion of K99/R00 awards for researchers from underrepresented populations.
    - Enforce the criteria for minority recruitment/retention plan (hold funding).
    - Expand K series awards available through NCMHD and NCI.
  - Incorporate training modules into future Summit meetings.
  - Develop strategies that address the unique challenges that MSIs face with recruitment, retention, and promotion:
    - Support both research and teaching tracks.
    - Provide access to the NIH library of journals.
    - Support faculty development.
  - Modify partnerships between research-intensive institutions and MSIs:
    - Require a minimum 50% release time for MSI investigators (MI/CCP).
    - Ensure that partnerships consider the realities of MSI faculty requirements/responsibilities.
Healthcare Professionals/Researchers
- Clinical trials investigators: solicit training funds for cancer health disparities research from pharmaceutical companies.
- Deans and chairs: create a system requiring senior faculty to mentor underrepresented faculty to promote diversity.

Community
- Work with state legislators to secure funds for health disparities research, scholarship, and training.
- Encourage national community organizations that include health activities to collaborate with researchers on health disparities research.

Key Points of Discussion

Training
- Minority Supplements. Inclusion of minority supplements in all grant mechanisms may be an easy way to increase training opportunities for minority/underserved populations.
- Funding for Doctoral Students in Health Disparities Research. Funding for doctoral students is critical because many investigators will continue in the field in which they received their degree. There is too little funding for doctoral students in health disparities research compared with other fields.

Health Policy
Facilitators: Erica Breslau, Ph.D., Program Director, Division of Cancer Control and Population Sciences, NCI
Howard Koh, M.D., M.P.H., Harvard University
Glen Mays, M.D., M.P.H., University of Arkansas

Priority Statement: Develop new health policy models or examine existing models to determine how they may be adapted to address cancer health disparities related gaps in your community, to translate research findings into policy, and to further engage local, state and Federal policymakers.

How can/do you use health policy models to help promote and sustain your cancer health disparities programs during times of increasing budget cuts?
- Use policy to generate funding (e.g., taxation).
- Institutionalize health policy structure.
- Use a multipronged approach (people, research, and legislature).
- Engage all levels of policy actors (including community, faith-based, associations, etc.).
- Use existing resources (e.g., Healthy People 2010, state cancer control plans) to guide work.
- Link to overarching health reform initiatives (e.g., MA Insurance Bill).

How can/do strengthened collaborations help you to maximize and leverage existing health policy models?
- Develop broad-based partnerships including the private sector (nongovernmental policy).
- Develop mentorship programs for minority professionals.
- Develop incentives for treating the under- and uninsured.
- Develop incentives for personal health promotion/screening.
- Create multilevel partnerships.
- Employ peer or novel advocacy/lobbying approaches.
- Develop/use databases and tracking systems to convey evidence.

**What recommended actions do you have for the following groups to help you adapt health policy models to address cancer health disparities related gaps in your community, translate research findings into policy, and further engage local, state and Federal policymakers so that your cancer health disparities programs are promoted and sustained?**

**NCI/NCMHD**
- Document the economic returns for investments in health disparities research.
- Identify national leaders as spokespersons.
- Make funding available for longer-term studies to show impacts on health disparities.
- Include a plenary session at next year’s Summit on health policy and cancer disparities/disparities reduction.

**Healthcare Professionals/Researchers**
- Create report cards on health disparities efforts to engage health care professionals/researchers.
- Provide incentives for professionals who work with the uninsured.
- Train professionals/researchers to lobby.

**Community**
- Reach communities with information on the laws that affect them.
- Empower individuals to advocate fervently.

**General**
- Change the way health disparities are discussed to convey the outrage over inequities.
- Empower communities to get involved.
- Train and increase advocacy efforts.

**Key Points of Discussion**

**Health Policy**
- **Local/State Universal Access to Care.** It is possible that health policy issues related to access to universal care will occur on a state-by-state basis, similar to tobacco control policy. Local governments may also play a role. San Francisco is close to approving universal access to health care for all.
- **Standardized Intervention.** Policies are needed that will translate what is already known into standardized interventions that will equally benefit different ethnic groups, particularly in the area of prevention.
- **Local Government Response to Health Disparities Data.** There is considerable variation in the responses of local/county governments to information, as well as the requests of their constituencies.
Overcoming Cancer Health Disparities

John Niederhuber, M.D., Acting Director, NCI

Dr. Niederhuber told meeting participants that he was pleased to attend the meeting that morning and wished he had been able to attend all of the sessions. He said he was looking forward to receiving the report from the meeting and hoped that resources could be found to make significant commitments to the needs of cancer health disparities research.

Dr. Niederhuber thanked Sanya Springfield, John Ruffin, Tarsha McCrae, Frank Jackson, and others who contributed to the planning and organization of the Summit.

Unprecedented progress is being made in many areas of science. There is an increased understanding of the biology of diseases like cancer. Knowledge has been gained about genetic abnormalities and how they relate to changes in cell signaling and communication. These changes have been related to tumor microenvironment, which can play a major role in the progression of cancer. However, issues dealing with health care delivery and health disparities have been more problematic. Difficulties getting the products of science to the people who need them the most continue to persist.

As a Cancer Center Director, Dr. Niederhuber struggled to find ways to reach out to the community as well as outlying rural areas and Indian reservations. He has realized that disparities have many faces. Disparities are not always due to financial resources or education; they are sometimes simply due to distance. Age can also be a barrier.

Dr. Niederhuber related a number of personal experiences that have shaped his view of health disparities and community outreach. When his wife was a breast cancer patient and had to fly across the country to participate in a clinical trial, Dr. Niederhuber realized that even well-educated patients with access to resources do not always have an easy time navigating cancer treatment. He recognized the difficulties of moving from universities into communities where care is primarily based in private, geographically scattered offices.

There is a need to decrease the time and cost it takes to introduce new agents into therapy. Both of these issues worsen the burden of disease by increasing health care costs.

NCI has identified health disparities as one of its eight strategic priorities; however, it must be remembered that this problem is not unique to the United States. As a country with resources and wealth and scientific capabilities, the United States must be an important player in this area around the world. There will be 10 million new cancer cases diagnosed in the world this year and over 87% of these will be outside the United States; 91% of the mortality from cancer will be outside of this country. This issue needs to be addressed.

John Seffrin, CEO of the American Cancer Society, said, “Access to the means, to the attainment, and preservation of health is a basic human need and a right, and should not be thought of as a privilege for the few.” This issue is not about the science—the science to cure disease will be there. The biggest determinant of cancer mortality in the future will be the ability to get the science to patients and the communities in which they live.

NCI has been working to develop a program that will build another rim of cancer care around the 61 outstanding university-based Comprehensive Cancer Centers. This rim will be composed of community-based centers and the program will attempt to create a way to bring the science—the earliest-phase clinical trials—to these centers. It is the responsibility of NCI to work in these community sites with research programs that will bring the science to patients. This will in turn facilitate the acquisition of tissue for larger scientific programs across the country as well as research on ways to better address the issue of disparities. It is hoped that six pilot sites for this program will be initiated in 2007.
The Government, the private sector, individuals, and society have specific roles to play in influencing the issues of health disparities. All of these groups must strive toward a more equitable distribution of new knowledge in order to reduce cancer mortality and the gaps between rich and poor, educated and uneducated, young and old, and between countries as well as within the United States.

Dr. Niederhuber ended by thanking the participants for the time they devoted to the Summit and for the work they have done in the area of health disparities.

**Key Points of Discussion**

- NCI will continue to work hard to be a good steward of the resources it is given. Meeting participants were urged to help NCI get more resources.

- The six pilot sites for the NCI Cancer Center-community project have not yet been selected. There will be more information made available on how interested communities can submit applications to be one of the pilots. The Center to Reduce Cancer Health Disparities has been heavily involved in the development of this concept and is hopeful that some of the pilot projects will reflect the importance of health disparities issues.

- The search committee assigned to identify candidates for the position of Director of the Center to Reduce Cancer Health Disparities has completed its task and will be presenting Dr. Niederhuber with a list of potential candidates. It is hoped that the process of naming a new Director will be completed in the next few months.

- Although minority populations represent 40% of the U.S. population, only 5.6% of the NCI budget is devoted to health disparities research. The NCI budget is 86% committed to ongoing projects, leaving very little discretionary budget. Furthermore, much of the research supported by NCI has a major impact on the ability to deliver scientific advancements to the population, even if that research is not labeled as health disparities research.

- Disparities exist in areas where there are no Comprehensive Cancer Centers. Many of these areas have programs that have relationships with the community and are able to reduce the discovery-delivery disconnect. It is hoped that the Cancer Center-community program will capitalize on these capabilities. Applicants to the pilot phase of the program will also be credited if they can demonstrate relationships with local or state governments.

- NCI and other NIH Institutes and Centers are funded to do research. Because of this, efforts funded by NCI to address disparities must be research questions, including questions about how to better do outreach or education. It is hoped that the knowledge gained from this investment in research will prompt others in the private sector or in other parts of the government—state, local, and Federal—to invest in the delivery of these interventions to the populations who need them.

- Many programs are doing more than outreach and delivery—they are performing community-based participatory research. Community involvement is essential for the design of population studies. Community-based research created the opportunity to examine relationships between genetics and environmental and other factors.

- The proportions of NCI investments in basic, translational, and clinical research have remained remarkably constant throughout the time of the NIH budget doubling and into the current time of a flattening NCI budget.

- Citizens need to get the message out that there are opportunities and that resources are needed to address the barriers to realizing these opportunities. Congressional representatives will listen to community representatives, particularly those who can talk to them about issues that are relevant in their districts.
Closing Remarks

*Sanya Springfield, Ph.D., Acting Director, CRCHD, NCI*

Dr. Springfield announced that the Center to Reduce Cancer Health Disparities will now be accepting unsolicited grants, including R01s and R03s. Also, CRCHD and the Comprehensive Minority Biomedical Branch will be recruiting applicants for new positions in order to build up their expertise across the entire continuum of cancer research in health disparities.

Dr. Springfield thanked Summit participants for taking the time to attend the Summit and for generating recommendations for CRCHD, NCI, and NCMHD. Dr. Springfield also strongly encouraged participants to engage their communities, cancer centers, and local institutions.

Dr. Springfield ended by thanking Tarsha McCrae, Frank Jackson, and other members of the planning committee for their efforts in planning the Summit.

*Derrick Tabor, Ph.D., Program Official, NCMHD*

Dr. Tabor informed participants that they had met with over 700 colleagues from across the country and attended over 80 poster presentations that addressed health disparities populations. They also attended an innovative session for sharing resources through which over 100 resources were made available to them.

Dr. Tabor ended by reminding Summit participants that the purpose of their activities is to ensure that one day all citizens will be able to realize the opportunity of living long, healthy, productive lives.
## Appendix – List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAPI</td>
<td>Asian Americans and Pacific Islanders</td>
</tr>
<tr>
<td>ACCC</td>
<td>Asian Community Cancer Coalition</td>
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<tr>
<td>ACCN</td>
<td>Appalachia Cancer Control Network</td>
</tr>
<tr>
<td>ACS</td>
<td>American Cancer Society</td>
</tr>
<tr>
<td>APIAHF</td>
<td>Asian and Pacific Islander American Health Forum</td>
</tr>
<tr>
<td>ATECAR</td>
<td>Asian Tobacco Education, Cancer Awareness, and Research</td>
</tr>
<tr>
<td>BCRP</td>
<td>Breast Cancer Research Program</td>
</tr>
<tr>
<td>caBIG</td>
<td>Cancer Biomedical Informatics Grid</td>
</tr>
<tr>
<td>CanCOR</td>
<td>Cancer Care Outcomes Research and Surveillance Consortium</td>
</tr>
<tr>
<td>CBPR</td>
<td>Community-Based Participatory Research</td>
</tr>
<tr>
<td>CCOP</td>
<td>Community Clinical Oncology Program</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CDMRP</td>
<td>Congressionally Directed Medical Research Programs</td>
</tr>
<tr>
<td>CDRP</td>
<td>Cancer Disparities Research Partnership Program</td>
</tr>
<tr>
<td>CEC</td>
<td>Cancer Expert Corps</td>
</tr>
<tr>
<td>CECCR</td>
<td>Centers of Excellence in Cancer Communications Research</td>
</tr>
<tr>
<td>CIS</td>
<td>Cancer Information Service</td>
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<tr>
<td>CMBB</td>
<td>Comprehensive Minority Biomedical Branch</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
</tr>
<tr>
<td>CNP</td>
<td>Community Networks Program</td>
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<tr>
<td>CRCHD</td>
<td>Center to Reduce Cancer Health Disparities</td>
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<tr>
<td>CRF</td>
<td>Cigarette Restitution Fund</td>
</tr>
<tr>
<td>CRIR</td>
<td>Cancer Research Interns in Residence</td>
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<tr>
<td>CSSI</td>
<td>Center for Strategic Science and Technology Initiatives</td>
</tr>
<tr>
<td>CTEP</td>
<td>Cancer Therapy Evaluation Program</td>
</tr>
<tr>
<td>CURE</td>
<td>Continuing Umbrella of Research Experiences</td>
</tr>
<tr>
<td>DCB</td>
<td>Division of Cancer Biology</td>
</tr>
<tr>
<td>DCCPS</td>
<td>Division of Cancer Control and Population Sciences</td>
</tr>
<tr>
<td>DCEG</td>
<td>Division of Cancer Epidemiology and Genetics</td>
</tr>
<tr>
<td>DCP</td>
<td>Division of Cancer Prevention</td>
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<tr>
<td>DCTD</td>
<td>Division of Cancer Treatment and Diagnosis</td>
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<tr>
<td>DoD</td>
<td>Department of Defense</td>
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<tr>
<td>ECR-LRP</td>
<td>Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>------------</td>
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</tr>
<tr>
<td>Project EXPORT</td>
<td>Centers of Excellence in Partnership, Outreach, and Training</td>
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<tr>
<td>FDA</td>
<td>Food and Drug Administration</td>
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<tr>
<td>HBCU</td>
<td>Historically Black Colleges and Universities</td>
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<tr>
<td>HDR-LRP</td>
<td>Health Disparities Research Loan Repayment Program</td>
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<tr>
<td>HHS</td>
<td>United States Department of Health and Human Services</td>
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<tr>
<td>HINTS</td>
<td>Health Information National Trends Survey</td>
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<tr>
<td>HPV</td>
<td>Human Papillomavirus</td>
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<tr>
<td>HRSA</td>
<td>Health Resources and Services Administration</td>
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<tr>
<td>I² Team</td>
<td>Integration/Implementation Team</td>
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<tr>
<td>IOM</td>
<td>Institute of Medicine</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>LRP</td>
<td>Loan Repayment Program</td>
</tr>
<tr>
<td>MBCCOP</td>
<td>Minority-Based Community Clinical Oncology Program</td>
</tr>
<tr>
<td>MI/CCP</td>
<td>Minority Institution/Cancer Center Partnership Program</td>
</tr>
<tr>
<td>MIU</td>
<td>Minority and Underserved Populations Program</td>
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<tr>
<td>MOA</td>
<td>Memorandum of Agreement</td>
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<tr>
<td>MOU</td>
<td>Memorandum of Understanding</td>
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<tr>
<td>MSI</td>
<td>Minority-Serving Institution</td>
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<tr>
<td>NACRP</td>
<td>Native American Cancer Research Partnership</td>
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<tr>
<td>NAICCO</td>
<td>Native American Indian Center of Central Ohio</td>
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<tr>
<td>NAU</td>
<td>Northern Arizona University</td>
</tr>
<tr>
<td>NCI</td>
<td>National Cancer Institute</td>
</tr>
<tr>
<td>NCMHD</td>
<td>National Center on Minority Health and Health Disparities</td>
</tr>
<tr>
<td>NHMA</td>
<td>National Hispanic Medical Association</td>
</tr>
<tr>
<td>NHOPI</td>
<td>Native Hawaiian and Other Pacific Islanders</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institutes of Health</td>
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<tr>
<td>NY-CATCI</td>
<td>New York Chinese American Tobacco Control Initiative</td>
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<tr>
<td>OC</td>
<td>Office of Communications</td>
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<tr>
<td>OCRP</td>
<td>Ovarian Cancer Research Program</td>
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<tr>
<td>OCTR</td>
<td>Office of Centers, Training, and Resources</td>
</tr>
<tr>
<td>OSPA</td>
<td>Office of Science Planning and Assessment</td>
</tr>
<tr>
<td>PCRP</td>
<td>Prostate Cancer Research Program</td>
</tr>
<tr>
<td>PLCO</td>
<td>Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial</td>
</tr>
<tr>
<td>PNRNP</td>
<td>Patient Navigation Research Program</td>
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</tbody>
</table>
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<tr>
<th>Acronym</th>
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<tbody>
<tr>
<td>PPI</td>
<td>Priority Populations Initiative</td>
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<tr>
<td>RFA</td>
<td>Request for Applications</td>
</tr>
<tr>
<td>RRP</td>
<td>Radiation Research Program</td>
</tr>
<tr>
<td>SBIR</td>
<td>Small Business Innovation Research program</td>
</tr>
<tr>
<td>SBTT</td>
<td>Small Business Technology Transfer program</td>
</tr>
<tr>
<td>SEER</td>
<td>Surveillance, Epidemiology, and End Results program</td>
</tr>
<tr>
<td>SELECT</td>
<td>Selenium and Vitamin E Cancer Prevention Trial</td>
</tr>
<tr>
<td>SPN</td>
<td>Special Populations Networks</td>
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<tr>
<td>SPORE</td>
<td>Specialized Program of Research Excellence</td>
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<tr>
<td>STAR</td>
<td>Study of Tamoxifen and Raloxifene</td>
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<tr>
<td>TReND</td>
<td>Tobacco Research Network on Disparities</td>
</tr>
<tr>
<td>TRIPS</td>
<td>Tobacco Research in Practice Settings</td>
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<tr>
<td>TTURC</td>
<td>Transdisciplinary Tobacco Use Research Center</td>
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<tr>
<td>UPMC</td>
<td>University of Pittsburgh Medical Center</td>
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