CONFERENCE SUMMARY REPORT AND RECOMMENDATIONS
June 2011


A catalyst in creating a community of ongoing learning and collaboration...

South Asian Total Health Initiative (SATHI)
Department of Pediatrics
UMDNJ-Robert Wood Johnson Medical School
http://rwjms.umdnj.edu/global_health/sathi/index.html

Center for Healthy Families and Cultural Diversity
Department of Family Medicine and Community Health
UMDNJ-Robert Wood Johnson Medical School
http://rwjms.umdnj.edu/departments_institutes/family_medicine/chfcd/index.html
June 20, 2011

Dear Colleagues,

We are pleased to share with you the attached document entitled, *Addressing Health Disparities and Health Literacy Challenges in the South Asian Community: Summary Report and Recommendations* from a National Conference held at the New Jersey Hospital Association, Princeton, NJ (October 9, 2010). This conference was co-sponsored by the South Asian Total Health Initiative (Department of Pediatrics) and the Center for Healthy Families and Cultural Diversity (Department of Family Medicine and Community Health) at the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School, and the Office of Minority and Multicultural Health of the New Jersey Department of Health and Senior Services. Funding support for the conference was provided by the New Jersey Health Initiative Program of the Robert Wood Johnson Foundation, Verizon Foundation, Lilly USA, and Merck & Co., Inc.

We hope that you will find this report to be an informative, meaningful, and helpful resource as it relates to your interest in improving the health and wellbeing of our state’s and nation’s increasingly diverse populations.

Sincerely,

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Addressing Health Disparities and Health Literacy Challenges in the South Asian Community

Summary Report and Recommendations
From a National Conference held at the New Jersey Hospital Association, Princeton, NJ
October 9, 2010

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SECTION 1.0: EXECUTIVE SUMMARY

A one-day conference held on October 9th 2010, in Princeton New Jersey (NJ) addressed the current state of health disparities and health literacy challenges in the South Asian community. The conference was co-sponsored by the South Asian Total Health Initiative at the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School (UMDNJ-RWJMS), the Center for Healthy Families and Cultural Diversity (UMDNJ-RWJMS), and the Office of Minority and Multicultural Health of the Department of Health and Senior Services of New Jersey (OMMH). This conference heralded a significant advance in our understanding of the health disparities that exist in the South Asian population since it was devoted entirely to this community. In almost all public health surveys, South Asians are combined with other Asian subgroups (e.g., Japanese, Chinese, Vietnamese), concealing the significant health disparities that exist for members of this sub-group. South Asians (i.e., people from Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka) are one of the fastest growing immigrant groups in the nation, having doubled their population in 2000 to 2.7 million of the US population. New Jersey is home to the third largest concentration of South Asians in the US (following New York and California). A recent report (March, 2011) from the New Jersey Department of Health and Senior Services entitled “The Health of the Newest New Jerseyans” reports that India provides the largest number of foreign-born New Jersey residents (11%) followed by Mexico (7%) and the Dominican Republic (6%). Furthermore, Indians (37%), Pakistanis (4%) and Bangladeshis (1%) represent a total of 42% of the foreign-born Asians in New Jersey.

- Considerable scientific evidence exists that South Asians are burdened by significant morbidity and mortality associated with chronic and costly diseases including cancer, coronary artery disease, diabetes, and infectious diseases. Little is known about how genetics, diet, exercise, and cultural practices affect risk factors for these chronic diseases or whether adequate treatment for these disorders is received. Furthermore, despite higher than average incomes and education, South Asians, like many other population groups, may be ill-equipped to address their health concerns because of limited health literacy suggesting the need for designing culturally appropriate interventions that improve access to healthcare, mental health, oral health, and social services. Although anecdotal evidence suggests high use of complementary and alternative medicine commonly found in South Asia (e.g., Ayurveda, homeopathy, yoga, meditation), what remains unknown is how these healing practices affect health-seeking behavior and how they are used in combination with or in preference to Western medical treatment.

The goal of this conference summary report is to provide recommendations to the New Jersey Department of Health and Senior Services (NJDHSS) that aim to address disparities in health and healthcare, improve health outcomes, and potentially reduce the costs associated with health disparities and health literacy challenges in the growing South Asian population.
SECTION 2.0: INTRODUCTION

2.1 Who are South Asians?

There are over two million South Asians (defined as persons from India, Pakistan, Bangladesh, Sri Lanka, Nepal, Bhutan and the Maldives) living in the United States, accounting for 6% of the total foreign-born population. As per the 2000 Census, Asians (which includes South Asians), overall formed 30% and Latinos 45% of the foreign-born citizens in the US. Furthermore, between 1990 and 2000, the Asian American community grew at a rate of 63%, one of the fastest growing ethnic groups in the nation. In particular, the fastest growing South Asian sub-groups between 1990 to 2000 were Indians, Pakistanis, and Bangladeshis growing at rates of 113%, 125%, and 350% respectively. Preliminary evidence from the 2010 US Census suggests that this growth trend continued from 2000 to 2010 as well.

The State of New Jersey has a particularly diverse population with representation from many different racial, ethnic, and socio-cultural groups. As per the 2010 census, foreign-born individuals account for 20% of New Jersey’s population compared to 11.1% nationally, and approximately a third (31%) of these individuals are from Asia. Languages other than English are spoken by 28% persons living in New Jersey as compared to 17.9% in the US.

As per the 2010 census, with approximately 200,000 South Asian residents, New Jersey has the third largest statewide population of South Asians in the US and one of the highest proportions (2.3%) of South Asian residents in the country. Furthermore, this community has experienced a phenomenal population increase in the State (approximately 133%) between 1990 and 2010. New Jersey’s South Asian communities are concentrated in three counties (Hudson, Bergen, Middlesex) with the largest concentration of South Asians in Middlesex County.

The South Asian community of New Jersey is diverse in terms of the country of origin, religious beliefs (e.g., Hindus, Sikhs, Muslims, Buddhists and Christians) and languages spoken (e.g., Hindi, Gujarati, Punjabi, Urdu, Marathi, Tamil, Telugu), making it one of the most complex and heterogeneous subgroups in the US. South Asians have the highest median income of any ethnic group in the US and over 70% of immigrants from India hold a bachelor’s degree while 40% have a Master’s degree often leading policymakers to the perception of a “model minority” with few health and social problems. Recent data, however, are documenting increasing heterogeneity in terms of economic and educational status, including the presence of a lower income subgroup employed in low wage jobs such as cashiers, taxi drivers, and restaurant workers, many of whom are living below the poverty level. Adding to this complexity is the fact that significant segments of South Asians have limited English proficiency.

2.2 Health Disparities in South Asians

Recent research studies from the United Kingdom and South Asia challenge the perception that South Asians are a “model minority” community, as findings suggest
that South Asians tend to carry a high burden of chronic disease, occurring at younger ages, particularly cardiovascular diseases, diabetes and metabolic syndrome. Recent reports also suggest that as many as 40% report not having a regular source of health care.

- The incidence, prevalence, hospitalization, morbidity, and mortality from coronary artery disease among South Asians are 50% to 300% higher than in Europeans and Americans. In fact, South Asians bear 60% of the burden of coronary artery disease in the world. In a study by Misra and colleagues, 43% of Indian Americans tested had higher than recommended total cholesterol levels and dyslipidemia. Dodani and colleagues report that these disparities may be explained by both high levels of LDL coupled with non-functioning HDL which has been linked to mutations of the Apo-A1 gene.

- Diabetes is also highly prevalent among South Asian adults who exhibit significantly higher rates of diabetes compared to other racial and ethnic groups and even other Asian groups. Further, South Asians experience coronary artery disease and diabetes approximately ten years before other ethnic groups leading to poorer quality of life.

- South Asian immigrants have a documented higher cancer risk, in particular, breast cancer, than South Asians living in South Asia. Furthermore, cancer prevention practices are low. Recent findings reported by the New Jersey Department of Health and Senior Services suggest that South Asians have a low rate of engaging in preventive health measures (e.g., cancer screenings).

- Foreign-born South Asians also form a large proportion of tuberculosis (TB) cases in the United States. From 2005 through 2009, the top five countries of origin of foreign-born persons with TB were Mexico, Philippines, Vietnam, India, and China. South Asian TB patients are younger and tend to develop extra-pulmonary tuberculosis more frequently as compared to other immigrant groups.

Christine Zarcadoolas and others have identified health literacy as one of the most important determinants of health outcomes. The National Action Plan to Improve Health Literacy has emphasized that low health literacy is particularly prevalent among racial and ethnic minorities and among populations with low English fluency. Like other immigrant groups, South Asians have difficulty in relating to the norms of the US healthcare system which can differ significantly from the systems in South Asia. South Asian immigrants are often less able to advocate for themselves due to perceived and real cultural and linguistic barriers. The extent of the impact of low health literacy on health outcomes among South Asians is gradually becoming recognized. Emerging data from the UK are documenting the benefit of culturally appropriate health education in diabetes outcomes in ethnic minorities including South Asians. Additionally, the relationship between physician-patient communication and health outcomes among South Asians has been described in at least one British study.
2.3 Commitment of New Jersey to Address Health Disparities in Ethnic Minorities

Historically, the State of New Jersey has held a strong commitment to reducing health disparities. A recent report by Hanlon identifies New Jersey as one of eight states that leads the country in including data from state and federal sources in order to reduce health disparities. In 2000, the Healthy New Jersey 2010 initiative was launched to promote health and prevent diseases. Since New Jersey is home to one of the nation’s most diverse populations, the New Jersey Department of Health and Senior Services (NJDHSS) has held three separate summits aimed at eliminating health disparities for New Jersey’s African American (1999), Hispanic (2000), and Asian American (2001) communities. Although all these initiatives resulted in much-needed strategies aimed at reducing health disparities in these ethnic communities, they did not specifically focus on South Asians.

In response to the emerging needs of this rapidly growing community, in June 2005 UMDNJ sponsored its first conference on South Asian health entitled “The South Asian American Conference: Developing an Agenda for Action to Address Health Disparities” followed by a conference in June 2007 entitled “South Asian Community and Disabilities: Raising Awareness, Facing Challenges, Accessing Resources”. These earlier conferences helped raise awareness about health disparities and disabilities issues affecting the South Asian population but did not examine the role played by low health literacy and socio-cultural factors in contributing to health disparities.

2.4 Conference on Health Disparities and Health Literacy in South Asians

To address this gap, a one-day conference entitled “Addressing Health Disparities and Health Literacy Challenges in the South Asian Community” took place in Princeton, NJ on October 9, 2010 (see Appendix 1). The conference was organized by the South Asian Total Health Initiative (SATHI) and the Center for Healthy Families and Cultural Diversity (CHFCD) at UMDNJ-Robert Wood Johnson Medical School, in collaboration with the University of Medicine and Dentistry of New Jersey’s Center for Continuing and Outreach Education (UMDNJ-CCOE). The conference was also co-sponsored by The NJDHSS Office of Minority and Multicultural Health. Funding support for the conference was provided by the New Jersey Health Initiatives Program of the Robert Wood Johnson Foundation, Verizon Foundation, Lilly USA, and Merck & Co., Inc.

A major goal of this conference was to raise awareness about the increased burden of chronic illness and health disparities experienced by South Asian communities, share best and promising for addressing these disparities, and generate recommendations for improving the health and well-being of the South Asian population in New Jersey. It was also focused on understanding the role of a major barrier to positive health outcomes: low health literacy. In 2010, the National Action Plan to Improve Health Literacy identified limited health literacy, affecting people of all ages, races, incomes, and education levels, as a significant roadblock to searching for and using health information, adopting healthy behaviors, and acting on public health alerts. This conference marked a significant advance in our understanding of the health disparities
that exist in the South Asian population and was the first national level conversation on
the subject of both health disparities and health literacy challenges affecting this diverse
community.

SECTION 3.0 CONFERENCE EDUCATIONAL SUMMARY

The conference learning objectives were the following:

1) Describe the impact of health disparities including low health literacy experienced by
South Asian populations in New Jersey,

2) Identify and apply best and promising practices to help patients/consumers with
health literacy challenges, navigate the health care system to reduce disparities, manage
chronic illnesses, and support prevention activities,

3) Employ innovative health education strategies including multimedia, music, and
mobile technologies to improve access, disease self-management, promote wellness and
integrative healing, and empower patients/consumers.

A total of 126 participants attended and there were 28 faculty members. Noted national
and local experts in health literacy, South Asian health disparities, and cultural
competence, presented two keynote addresses on health disparities and health literacy,
a plenary panel discussion on interfacing health literacy with selected initiatives in
cardiovascular health disparities, culturally competent health care, and
provider/consumer health education; three workshops focused on health disparities in
diabetes, cancer, and tuberculosis and three workshops focused on innovative strategies
to address health disparities including complementary and alternative medicine,
followed by a closing session focused on generating and summarizing recommendations
and future action steps.

Physicians, nurses, other healthcare professionals, educators, and researchers were
invited through the CCOE, SATHI, and CHFCD networks. Providers who serve the
South Asian community were invited via the SATHI newsletter, email, print media, and
direct mail of brochures/flyers as well as through hospital contacts SATHI has
established. Consumers, mainly people of South Asian origin were reached through the
distribution of brochures/flyers at health fairs, the print media (press releases in local
South Asian newspapers), emails and other web-based marketing tools.

Additional health care and public health organizations were invited to participate
including the New Jersey Hospital Association, New Jersey Primary Care Association
and Federally Qualified Health Centers, New Jersey Department of Health and Senior
Services, New Jersey Public Health Association, the New Jersey Society for Public
Health Education, Literacy Volunteers of New Jersey, the New Jersey Statewide
Network for Cultural Competence, and the UMDNJ-School of Public Health/Institute
for the Elimination of Health Disparities.
South Asian Mental Health Awareness in Jersey (SAMHAJ), a program of the National Alliance on Mental Illness of New Jersey (NAMI-NJ) and South Asian Americans Leading Together (SAALT), a national organization that advocates around issues affecting South Asian communities, were also invited to participate in the conference organization and promotion.

By involving these community representatives, the organizers were able to incorporate the perspectives of South Asian healthcare providers, community leaders and consumers during the conference planning and presentations as well as in providing recommendations for this report.

SECTION 4.0 SUMMARY OF CONFERENCE SESSIONS

The Conference was opened with remarks from the New Jersey Health and Senior Services Commissioner, Dr. Poonam Alaigh, New Jersey Assemblyman Upendra Chivukula, Dean of UMDNJ-Robert Wood Johnson Medical School, Dr. Peter S. Amenta and conference co-chairs Drs. Sunanda Gaur, Naveen Mehrotra and Robert C. Like

- The Health Commissioner pointed out that the proceedings from the conference can provide a roadmap and framework of what individual states can do to improve the healthcare for immigrants and the South Asian community particularly. She also read a letter from New Jersey Governor Chris Christie recognizing the need for this conference: “With a tremendous influx of South Asian immigrants into New Jersey, now is the time to evaluate professional care, treatment, and educational practices to the population. Establishing a well-received dialogue in this community is essential to the health and prosperity of our residents”.

- The Assemblyman highlighted the fact that South Asians are one of New Jersey’s fastest growing subgroups among the growing Asian American population in the state. He also read from a proclamation from the New Jersey Assembly which highlighted the importance of addressing health disparities and health literacy challenges and that the recommendations for addressing these challenges will impact on “clinical and preventive care, public health practice, education, research, and health policy”.

- The dean commented that improving community health is critical to achieving excellence in both medical education and patient care. He also emphasized that the sessions from the conference can provide a springboard for developing “best practices” in treating South Asian patients.

- The conference co-chairs welcomed the participants and charged them to learn about the current state of health disparities and health literacy within South Asians, to use the opportunity to network with other participants and most importantly with providing recommendations that will inform a statewide agenda focused on improving health disparities and health literacy of one of New Jersey’s growing immigrant populations.
In sections 4.1 through 4.5, key concepts, research findings, and recommendations for future work are provided for the two keynote addresses, the plenary panel discussion, the three workshops focused on health disparities and the three workshops focused on innovative strategies for addressing disparities and health literacy challenges.

4.1 Addressing Health Literacy Challenges in Multicultural Communities: Best and Promising Practices

The first keynote address speaker reviewed the current state of knowledge about health literacy and the implications this has for clinical care, public health, education, research, and health care policy and the need for creating “communities of practice” by bringing together key stakeholders and constituency groups in collaborative efforts.

The following important messages emerged from this session:

- What is health literacy? Health literacy is the wide range of skills and competencies that people develop over their lifetimes to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, and increase quality of life.
- Health literacy is a major public health and clinical challenge. There are estimates that close to 70% of the general US population have limited health literacy.
- Half the US population reads at 8th grade level or below; most health information is provided at grade level 10 and higher and web-based health information is presented at an even higher grade level. This results in low levels of basic health knowledge. For example, 70-90% of the population does not know the difference between a virus and bacteria.
- Health literacy interventions need to address the needs of our increasingly diverse population.
- To deal with chronic diseases, engaged and informed patients are required.
- Good health outcomes are dependent on clear communication between the health care providers and patients. The emphasis is on the healthcare system and provider to ensure clear communication during transfer of ideas and knowledge.
- Health literacy needs to address 4 areas of literacy: (a) fundamental literacy which encourages clear, understandable language and visuals, (b) science literacy which includes education about risk factors, knowledge about how the body works to result in positive and negative health outcomes, (c) civic literacy which includes understanding environmental and social factors that affect health outcomes, and (d) cultural literacy which includes understanding cultural patterns of health behaviors (or lack of) and begin to change them.
- Technology and social media play an increasingly important role in addressing low literacy levels.
4.2 Addressing Health Disparities and Chronic Illness in South Asian Communities: What We Know and What We Don’t Know

The speaker during the second keynote address discussed the current understanding of health disparities affecting South Asians. She also shared her findings from the first US-based nation-wide study on diabetes and Asian Indians (The DIA Study) conducted by her group, and outlined future research needs.

The following important messages emerged from this session:

- South Asians are the second fastest growing racial group in the US and have one of the highest rates of cardiovascular disease and diabetes.
- Asian/Pacific Islanders (South Asians are often categorized under this group) have the lowest rates of attending wellness checks, pap smears, mammograms, and cholesterol checks. 20% report family history of cancer but low rates of breast and testicular cancer screenings.
- Asian Indians have one of the highest oral, breast, and cervical cancers rates in the world but the lowest stomach cancer rates.
- DIA (Diabetes among Indian-Americans) Study included Asian Indians in the US and compared them to a sample from India. Approximately 1900 participants were surveyed and blood work collected for 50-60% of them.
- DIA Study Findings:
  1. Asian Indians have highest rate of coronary artery disease in the world and tend to have it at younger ages;
  2. High C-reactive protein, high levels of triglycerides and LDL and dyslipidemia are prevalent;
  3. 17% had diabetes and an additional 33% had pre-diabetes; 25% did not know diagnosis;
  4. 70% were not aware that gestational diabetes is a risk factor for developing diabetes;
  5. Many are misinformed that simply eating a vegetarian (i.e., non-meat diet) means eating a “healthy diet” rather than understanding that including foods with high nutritional value (e.g., vegetables), decreasing carbohydrates (e.g., white rice) and preparing food using healthy fats (e.g., cutting out ghee) is also important;
  6. South Asians have higher percentage of body fat therefore Body Mass Index (BMI) cut-offs may need to be revised lower to improve detection of risk factors for chronic physical diseases including metabolic syndrome;
  7. Those who do not have access to regular medical care are 4 times more likely to use Complementary and Alternative Medicine (CAM) than those with access;
  8. Females use CAM at a higher rate than males;
  9. Those who do not speak English are more likely to use CAM (89% of those who use CAM do not speak English “very well”);
  10. Religious and spiritual people more likely to use CAM.
- Non-functional HDL may be reason for low levels of HDL; 6 polymorphisms found in Epo-A1 protein which may be the cause of the non-functional HDL;
current studies are investigating whether niacin supplements may improve HDL function among Asian Indians.

- Given high levels of risk for chronic diseases, preventive behaviors need to be emphasized.
- Collection of health-related data and statistics in aggregate, whereby South Asians are classified under AAPI (Asian-American and Pacific Islanders) leads to misinformed data regarding health issues of a specific subgroup. Efforts need to be made to collect disaggregated data.
- Further research is needed in understanding the biologic and socio-cultural causes of the health disparities seen in South Asian immigrants.

4.3 Plenary Panel: Interfacing Health Literacy with Selected Initiatives in Culturally Competent Health Care, Cardiovascular Health Disparities, and Provider/Consumer Health Education

4.3a. Improving Cardiovascular Health Disparities

The first plenary panel speaker focused on the development of an intervention that was targeted and tailored to the South Asian population using community-based participatory research (CBPR). The key findings from her studies are provided below:

- South Asians are at higher risk for developing cardiovascular disease compared to other ethnic groups; have high rates of being overweight and obese, do not often engage in physical exercise, and despite having a vegetarian diet, consume far fewer vegetables and fruits.
- The goal of study was to design a culturally-targeted, health literacy appropriate intervention that provides education about risk factors for cardiovascular disease and increases preventive health behaviors. Culturally-targeted means that in order to increase receptivity of the health messages one first needs to recognize, reinforce, and expand upon the target community’s perspectives of illness, normative values, beliefs and practices, to provide context and meaning to disease prevention messages.
- Evidence of lifestyle interventions are unknown in this population especially how to deploy interventions in those from low socioeconomic class and non-English speakers.
- The speaker described creation of cardiovascular prevention videos in collaboration with community members.
- She used community-based participatory research methods: 75 qualitative interviews conducted to understand how South Asians think about health and disease and 270 quantitative surveys completed on knowledge about heart disease, barriers to healthy lifestyles, and attitudes about health disease.
- Data revealed a strong belief that “shocking events” or “stressful life events” caused heart attacks and that they are not preventable.
- The goal of the intervention was to improve understanding of how heart attacks can occur using biomedical framework and also include information on reducing stress to address health beliefs of the population.
4.3b. Culturally Competent Health Care

The second plenary panel speaker provided a review of theoretical concepts that help in developing culturally competent health care practices. Major points from his talk are provided below:

- Proximal, intermediate and distal factors affect whether culturally competent care is delivered. Proximal factors include public policy, discrimination, social conditions, etc. Intermediate factors include whether provider is linguistically and culturally “compatible”. Distal factors include health-seeking beliefs of the consumer.
- Weaver suggests health-seeking behaviors occur when symptoms affect functioning. Some Asians may not report pain and “explain away” milder symptoms which results in less health care seeking behaviors.
- Health care seeking behaviors often viewed from the prism of how society will view this behavior and how this will affect the family.
- Barriers to seeking help:
  1. CAM is very popular among South Asians. They bring back Ayurvedic and homeopathic remedies from South Asia when they travel. Many South Asians employ CAM treatment first instead of seeking medical care.
  2. Families play important role: this sometimes creates challenges in decision making (who should decide – the individual or the family?);
  3. Higher tolerance or decreased expression of pain symptoms in some patients can result in late visits to healthcare providers;
  4. Genitourinary and mental symptoms are highly stigmatized which can result in low healthcare access for these types of problems;
  5. Gender and cultural preferences of patients vary;
  6. Limited knowledge of entitlement and social support programs and low knowledge of respite, preventive, and early intervention care;
  7. Lack of trust results in decreased adherence to treatment recommendations.
- Health care providers need to avoid stereotyping and over-generalizing given the heterogeneity that exists in the population.

4.3c. Provider and Consumer Health Education

The third plenary panel speaker discussed efforts underway to develop the New Jersey Health Literacy Coalition (www.njhealthliteracy.org). as well as similar initiatives in other states that are improving professional and consumer awareness about low health literacy, offering education and training, sharing resources, and engaging in research on effective health literacy interventions. Key points from her talk are included below:

- National Action Plan to Improve Health Literacy and various institutional and community-based efforts are ongoing in New Jersey and other states.
- New Jersey held its first Health Literacy Summit in April 2009. There were 200 attendees including representatives from Health Literacy Missouri, Wisconsin Literacy, New York City literacy and Baby Basics (training for expectant mothers
with limited literacy). Question was posed whether there was a need for a statewide health literacy coalition. Response was a resounding “yes”.

- In June, 2009, a statewide (New Jersey) organizational meeting was held. Fifty organizations participated and decided to develop a not-for-profit organization whose mission it was to improve health outcomes, increase efficiency of health care system, and improve communication between health care professionals and the diverse communities they serve.

- The coalition will adhere to recommendations put forth in the National Health Literacy Plan released by the Department of Health and Human Services in May 2010.

- An example of health literacy initiatives include the “Health Literacy Universal Precautions Toolkit” developed by Dr. Darren Dewald, at University of North Carolina.

- In June 2010, a seminar was held at Cancer Institute of New Jersey to discuss interface of health literacy and cancer outcomes.

4.4 Selected Health Disparities Workshops

The workshops consisted of three sessions devoted to: 1) Selected Health Disparities. Conference attendees were able to select 1 of 3 participatory workshops related to these themes. Each workshop focused on (a) challenges faced by clinicians, public health professionals, educators, researchers, community leaders, and consumers; (b) state of research on the topic; and (c) best and promising practices and existing resources.

4.4.1a Cancer

The presenters in this session focused on various health care options and resources available to clinicians, patients/consumers and their families who are dealing with cancer, and how they can best utilize these resources. Cultural and linguistic challenges faced in navigating the health care system were discussed and best and promising practices were shared.

- Data registries from New Jersey Department of Health suggest ~ 160 South Asian cancer cases annually: ~ 40 lung cancer, ~ 80 breast cancer and ~ 40 colon cancer. But registries can have missing data or misclassification of race because errors in charting can occur. Oral, cervical, and breast cancer are most concerning conditions for the community.

- Clinicians need to improve their definition of a cancer diagnosis, specifying the best preventive measures, improving early detection campaigns, and developing best and promising practices for interventions tailored for sub-populations such as South Asians.

- Health care workforce needs education about family dynamics affecting the treatment planning process and about the importance of doctor-patient communication and beliefs regarding pain management/end of life issues in South Asians. They need to develop an understanding of the socio-cultural
beliefs and practices relating to health promotion, disease prevention, diagnosis, treatment, rehabilitation, supportive care, palliative and end-of-life care.

- Assumptions of the “model minority” myth may suggest South Asians are health literate but underestimate the need for addressing literacy challenges. South Asians currently engage in low rates of screening: Pap smear, mammograms, and colorectal screenings.
- There is a need to develop support for families who require assistance and have a lack of extended families after immigration.
- Many South Asians also believe tobacco (smoked or smokeless), has medicinal value for curing or palliating common discomforts such as toothache, headache, and stomach ache. These misperceptions need to be corrected through social media and other educational campaigns.

4.4.1b Diabetes

This session focused on current research on diabetes in South Asians and complications such as vision loss related to diabetes. Strategies for bridging the gap between South Asian diet/cooking habits, physical activity, and diabetes were explored. Best and promising practices along with information on epi-genetics and nutrient-gene interactions and available diabetes-related support services (e.g., low-vision services from the New Jersey Commission for the Blind and Visually Impaired (CBVI) were also shared.

- Risk for diabetes and metabolic syndrome begins at a lower BMI at younger ages for South Asians. Misra’s study of Asian Indians documents that 17% of individuals screened met American Diabetic Association (ADA) criteria for diabetes and 33% met criteria for pre-diabetes (metabolic syndrome).
- Nutrition: high fat diets, westernization of diet and low physical activity after immigration promotes development of diabetes (Average HBA1C levels increase from rural to urban migration and from immigration from South Asia to the West; suggesting poorer glycemic control).
- Those with diabetes or pre-diabetes rate their health as “good”, despite presence of medical conditions.
- The issue of defining “diabetes” for this population is a major obstacle to early detection and treatment. It may not be appropriate to use current norms.
- An important goal for educational efforts will include improving the understanding of the health care workforce regarding lower thresholds for blood glucose for this community. The medical fields need to use other indices of diabetes that are less prone to day-to-day variations (e.g., HBA1c vs. fasting blood sugar reading).
- Consumers need to improve physical activity and integrate it into daily living tasks. They need to be educated on the importance of improving cholesterol levels and engage in regular blood glucose screening.
- Consumers need to become aware of available services in the community for diabetes-related complications (e.g., vision screenings provided by NJ CBVI across 23 counties in NJ).
4.4.1c Tuberculosis

The presenters in the Tuberculosis (TB) session outlined the latest TB epidemiological trends in the US and NJ and focused on barriers related to early diagnosis and appropriate treatment of patients diagnosed with TB. They also presented on the illness beliefs and stigma often associated with TB in South Asians. Additionally, the need to understand extra pulmonary manifestations of TB in this population was highlighted through the personal story of the session moderator.

The following were the major themes and recommendations that emerged:

- In the US, foreign-born individuals make up almost 60% of all newly reported cases in recent years. From 2005 through 2009, the top five countries of origin of foreign-born persons with TB were Mexico, Philippines, Vietnam, India, and China. In 2009, approximately 80% of TB cases in the US were among racial and ethnic minorities especially among Hispanics and Asians.
- Between 2005 and 2009, of the 1701 new cases of TB reported in New Jersey, 23.9% of these were among South Asians; the vast majority were individuals from India.
- Health care professionals need to be educated about the high prevalence of TB in foreign-born individuals. In particular, health care professionals need to understand that South Asians often present with extra-pulmonary manifestations of TB. In addition, the need to offer HIV testing in TB-infected persons needs to be communicated.
- Health care professionals also need to understand how to diagnose and treat latent TB particularly in those who have received the BCG vaccine.
- There is a need to increase awareness in community members that TB still exists among South Asians and to study barriers to accessing care and treatment adherence.
- The signs and symptoms of TB, issues surrounding communicability and involvement of the public health department, the need to complete treatment to prevent development of multiply resistant TB bacteria and the need for HIV testing needs to be conveyed to the South Asian community in a culturally appropriate fashion. Simplified educational resources need to be made available in various South Asian languages. Increased utilization of outreach personnel with fluency in South Asian languages might help promote understanding of the disease among consumers.
- Efforts need to focus on dispelling myths and stigma surrounding TB infections.
- UMDNJ-New Jersey Medical School Global Tuberculosis Institute has developed several resources for delivering culturally competent care related to TB care and treatment. These resources are available for health care practitioners as well as field workers.
4.5. Innovative Strategies Workshops

The workshops consisted of three sessions devoted to **Innovative Strategies to Address Health Disparities**. Conference attendees were able to select 1 of 3 participatory workshops related to these themes. Each workshop focused on (a) challenges faced by clinicians, public health professionals, educators, researchers, community leaders, and consumers; (b) state of research on the topic; and (c) best and promising practices and existing resources.

4.5.1a. Chronic Disease Management

This session included presentations by the facilitators in the Chronic Disease Self-Management Program (CDSMP; developed at Stanford University supported by NJDHSS). Presentations focused on pilot implementation of this program in the South Asian community. Cultural and linguistic barriers to disease management were discussed and strategies to address the gaps were explored. Two presenters also focused on how chronic disease self-management relates to diagnosis and management of mental illness.

Key findings from this presentation included:

- The CDSMP Program was welcomed by South Asian non-profits and community members.
- Increased awareness of the risk factors for chronic diseases in the South Asian community was established especially for diabetes, obesity, and heart disease.
- The program required excellent coordination between health care providers and CDSMP program facilitators.
- Difficulties faced in implementing the program included (1) lack of transportation to CDSMP program sites, (2) culturally-supported health beliefs were at times barriers to change in health behaviors, and (3) lack of a central community center where South Asians could gather to receive information regarding health.
- A critical goal for continued efforts at dissemination include exploring strategies to bring this evidence-based and effective chronic disease self-management program to greater number of South Asians in NJ. Expanding the availability of this program to a broader range of community-based organizations may help overcome some of the barriers.

The following key findings emerged regarding chronic disease self-management and its relationship to mental illness.

- Studies in the UK suggest higher mental illness burden in South Asians than in Whites. South Asians generally wait until symptoms are severe before accessing health services (usually in the Emergency Department).
- There is a need to address mental health concerns during primary care visits
- Healthcare providers need education regarding how to appropriately (with patients’ permission) include family members in treatment decisions when clinically indicated.
- Treatment challenges include: lack of trust in psychotherapy, poor medication adherence, fear of side effects, use of CAM, and stigma regarding mental illness diagnoses and treatment.
- A critical research goal is to improve data collection efforts on US-based South Asians as there are no studies on the prevalence of mental illness in this group.
- Community education efforts need to address issues of stigma and privacy when working within a family. Despite having higher than average income and education, a need for health literacy education efforts focused on identifying mental illness and identifying the differences between depression, anxiety, and somatic complaints and serious psychotic disorders is evident.
- An important recommendation emerged that community leaders (i.e., especially religious leaders) should emphasize that addressing chronic health conditions (including mental health) are important facets of practicing spirituality and religion.

4.5.1b Multimedia, Music and Mobile Technologies: Delivering Health Care Messages

In this session, research was presented about the development of Multimedia solutions for health promotion, disease prevention, and chronic illness care, including e-health programs that employ cell phone text messaging for improving patient medication adherence and patient education. Mobile (mHealth) technologies are also increasingly being used in health care to improve the health of individual patients.

A practicing family physician from Queens, New York, also spoke about the effectiveness of using hip hop songs for teaching about health, illness, and disease prevention. He described how Health-Hop® (http://www.healthhopmusic.com/healthhop.htm), a new music genre that he developed, is being used effectively to provide young people with medical information about conditions such as asthma, sickle cell disease, HIV prevention, H1N1 immunizations, healthy diets, and mental health problems. Other innovative approaches such as the use of films, dance, and Bollywood songs to deliver health messages to South Asians were also discussed.

- Healthcare providers and public health professionals need to think about the audiences to whom they send health messages.
- 75% of teens have cell phones (up from 45% in 2004) and they send 50-100 texts/day.
- Nearly as many teens and young adults use social networking sites and spend up to 12 hours a day consuming media (internet 5 hours/day; television 2.5 hours/day, mobile device 2.4 hours/day; mp3 player 1.3 hours/day and gaming device .75 hours/day.
- Existing and emerging smart phone technologies show promise for disseminating health messages although there is a need to address a host of privacy and funding issues.
Innovative approaches such as music, song, dance, and other multimedia are increasingly being employed in schools and community health education programs.

Health-Hop® has been used successfully with young adults/adolescents to raise awareness about asthma, diabetes, depression, HIV/AIDS prevention, nutrition, and other health-related issues.

4.5.1c Integrative Healing: Alternative Medicine and Spirituality

An internal medicine physician certified in endocrinology discussed techniques of meditation in the management of chronic illness in his patients. A Master yoga teacher and a certified Reiki practitioner described these modalities. A physician trained in family medicine, preventive medicine, and Ayurveda (traditional Asian Indian health system), gave a brief overview of Ayurveda and its use in the South Asian community.

The South Asian culture uses integrative practices in the disease management of many illnesses. Alternative and non-traditional medicines can sometimes be the primary form of medical management and the treatment modality of choice due to the belief that these treatments are more effective with better side-effect profiles. Mistrust of Western medicine can result in mainstream use of herbal treatments, Ayurveda, spirituality and yoga as a way of life and as treatment for illnesses in this community. These concepts and description of several of these modalities were discussed in this session.

Several forms of integrative healing practices have a significant following in US-based South Asians, 63.2% of the Asian Indian population sampled by Misra and colleagues used CAM. These treatment modalities may include use of herbs and healing practices such as Ayurveda, yoga, meditation, and others.

Health care practitioners need to be mindful and aware that patients may engage in alternative medicine practices. These practices may be integrated with the traditional prescribed treatment modality or may actually replace the recommended form of treatment.

Interaction of complementary and alternative medicine (CAM) with Western forms of treatment may lead to ineffectiveness of the physician prescribed medical management. Also, potential toxicities and interactions from CAM use would need to be highlighted to ensure effectiveness of the prescribed medical treatment.

Health care practitioners need to acknowledge and be respectful of the choices that the South Asian community might make in selecting these modalities either as integrative or alternative forms of therapy.

Health care practitioners need not alienate their patients who use these modalities but rather guide them to make the proper choices for best integrative practices for healing. Providers may find the Berlin and Fowkes LEARN model helpful to incorporate as a part of their medical history interview. (L- Listen with sympathy and understanding to the patient's perception of the problem. E- Explain your perceptions of the problem. A- Acknowledge and discuss the differences and similarities. R- Recommend treatment and N-Negotiate agreement).
- The health care community needs to participate in and generate research findings about the benefits and risks, effectiveness, and outcomes of alternative, complementary, and integrative healing modalities.

SECTION 5.0 RECOMMENDATIONS

The following General Recommendation and list of Specific Recommendations relating to 1) Policy Planning and Resource Development; 2) Data Collection and Research; 3) Community Education and Professional Training; and 4) Networking and Partnerships were generated from the keynotes, plenary panel discussion, workshops, and closing discussion.

General Recommendation

The New Jersey Department of Health and Senior Services (NJDHSS), through collaborations with other governmental and interested public and private sector partners, should play a leading role in spearheading and championing initiatives designed to address health disparities, health literacy, and cross-cultural service delivery challenges affecting the South Asian and other “Newest New Jerseyan” communities.

Specific Recommendations

Policy Planning and Resource Development

1) Increase awareness of policy makers – at state, regional, and national levels of the needs and strengths of the South Asian community.

2) Develop a state-level South Asian Health Advisory Commission (SAHAC) with representation from public health, clinical practice, academia, community, research, policy, and industry, to assist the NJDHSS in understanding the health disparities, health literacy challenges, and health-related cultural issues in this diverse community.

3) Ensure that health disparities, health literacy, and cultural competency initiatives in New Jersey are appropriately targeted and tailored to multicultural populations including South Asian and other “Newest New Jerseyan” communities.

4) Take steps to align New Jersey’s health promotion and disease prevention, health disparities, and health literacy plans with existing national plans.

5) Convene a statewide results-oriented South Asian Summit based on the feedback from this 2010 conference to further disseminate information about health disparities and health literacy issues to key stakeholders and interested constituencies, including focused conferences to explore specific topic areas and emergent issues.
Data Collection and Research

1) Improve data collection of Asian subgroups as requested in the 2007 “Race and Ethnicity Coding Guidelines” from the NJDHSS (a product of the state’s Strategic Plan to Eliminate Health Disparities). Encourage disaggregation of data at national level (other states) and develop a national level plan to collect data on health-related risk factors, clinical prevention and screening practices, and on specific diseases including cancer, cardiovascular disease, diabetes, tuberculosis, depression, anxiety, and other mental illnesses in South Asians.

2) Facilitate focus groups in the South Asian community to understand the health beliefs and practices and issues relating to access to care to develop culturally targeted tools that will aid in public health campaigns that reach across health literacy levels (i.e., community-based participatory research).

3) Issue Requests for Proposals (RFPs) that encourage academic institutions to engage and partner with community groups. Community-based participatory research (CBPR) efforts are needed to improve data and empower constituent groups. Encourage collaborative research partnerships involving several minority and multicultural populations (e.g., Hispanics/Latinos, African Americans, Asian Americans) to submit joint grants to fund initiatives on education, research, and other shared concerns.

4) Develop research initiatives to determine how chronic disease self-management type programs can be disseminated in South Asian and other minority and multicultural communities. Collect evaluation data at the state level on whether preventative and self-management programs are effective in these communities.

5) Conduct focus groups to ensure health education materials are targeted to the health literacy needs of the audience, are culturally appropriate, and are available and understandable in multiple languages and formats (e.g., print, multimedia, web-based).

Community Education and Professional Training

1) Disseminate knowledge through public health campaigns and consumer education campaigns regarding existing research findings that relate to South Asian health disparities and risk factors for cancer, diabetes, cardiovascular disease, infectious diseases (including tuberculosis), and mental illness. Address low health literacy of the community by disseminating information that is accurate, accessible, and actionable.

2) Develop public health campaigns that reduce stigma associated with various disorders including tuberculosis, mental illness, and cancer.

3) Provide cultural competency, health disparities, and health literacy training for New Jersey’s health care organizations, medical, nursing, public health and allied health professionals, and public health schools relating to issues prevalent specifically in South Asians.
4) Educate health care providers that they need to address chronic diseases such as cancer, mental illness, diabetes, and cardiovascular disease, and recognize various manifestations of tuberculosis (e.g., extra-pulmonary TB and latent TB) in persons arriving in New Jersey from South Asian countries.

5) Increase health care providers’ understanding about medical pluralism and the use of integrative healing modalities in the South Asian community. Improve professional and consumer knowledge about the risks, benefits, effectiveness, and outcomes of complementary and alternative medicine (CAM) use, and how to communicate more respectfully in negotiating mutually acceptable treatment plans.

**Networking and Partnerships**

1) Work collaboratively with other national, state, and local organizations that are developing health literacy interventions and make use of social marketing, networking, and web-based technologies.

2) Encourage collaboration with New Jersey’s Health Literacy Coalition to develop health literacy interventions that target lifestyle risk factors by increasing focus on how we can translate and adapt lifestyle interventions in minority communities, and involve the community in actually designing health education messages for South Asians.

3) Encourage and support public health programs, health care organizations, and academic institutions to partner with community and other non-profit organizations to provide opportunities for the South Asian community to participate in preventive health screenings.

4) Develop partnerships between New Jersey Department of Health and Senior Services, Office of Minority and Multicultural Health (OMMH) with its sister agency, New Jersey Department of Human Services, Division of Mental Health and Addiction Services (DMHAS), to explore opportunities for collecting data and developing interventions to address mental health disparities that exist for South Asians.

5) Encourage public–private partnerships as sources of funding for initiatives to eliminate health disparities in South Asians. These include partnerships with the telecommunications industry to develop mHealth and eHealth technologies, and with the entertainment industry to disseminate health messages using culturally appropriate media (e.g., Bollywood films that address health topics; use of classical, film, or bhangra music to increase awareness of health–related risk factors).

**SECTION 6.0 CONCLUSIONS**

This conference summary report should be seen as a “work in progress” and a “living and evolving document.” The recommendations presented will hopefully generate further engagement, discussion, and concerted action to address the health disparities, health literacy, and cross-cultural service delivery challenges experienced by the South Asian community and other minority and multicultural communities in New Jersey. We
hope the support and recognition of the need for this dialogue by the New Jersey Office of Minority and Multicultural Health (NJDHSS), Assemblyman Upendra Chivukula, and past New Jersey Commissioner Poonam Alaigh will lead to continued conversations with and support from the current and future New Jersey administrations. It is our hope that this Call to Action will result in partnerships and collaborations that can successfully implement “best and promising practices” in the field. We welcome feedback and ongoing dialogue with other interested individuals and organizations.
Disclaimer

Please be advised that the ideas and opinions expressed in this report are those of the authors, and are not necessarily those of the organizations with which they are employed or affiliated, the conference presenters or funders, the University of Medicine and Dentistry of New Jersey, or the New Jersey Department of Health and Senior Services.

Acknowledgements

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SECTION 7.0 REFERENCES


SECTION 8.0 APPENDICES

Appendix 8.1

Conference Brochure (attached)

Appendix 8.2

About South Asian Total Health Initiative (SATHI)

The South Asian Total Healthcare Initiative (SATHI), a program of the University of Medicine and Dentistry of New Jersey – Robert Wood Johnson Medical School (UMDNJ-RWJMS) Department of Pediatrics (http://rarwjms03.umdnj.edu/global_health/sathi/index.html) is a comprehensive, multifaceted initiative to improve the delivery of culturally competent healthcare and information about total health for the South Asian community, and the education, engagement and empowerment of the community to improve health outcomes.

SATHI’s mission is to:

1) Establish a centralized location for research on South Asian health
2) Improve the delivery of culturally competent care, address disparities in health and health care
3) Educate, engage and empower the South Asian community to promote wellness and improve health outcomes
4) Provide technical assistance and consultation to health care policy makers and other key stakeholders and constituency groups.

Detailed information about SATHI activities is attached.

About the Center for Healthy Families and Cultural Diversity (CHFCD)

The Center for Healthy Families and Cultural Diversity (CHFCD) in the Department of Family Medicine and Community Health, UMDNJ-Robert Wood Johnson Medical School (http://rwjms.umdnj.edu/departments_institutes/family_medicine/centers_networks/chfcd/index.html) was established in 1997, and is dedicated to leadership, advocacy, and excellence in promoting culturally-responsive, quality health care for diverse populations. The CHFCD recognizes that persisting racial and ethnic disparities in health and health care are major clinical, public health, and societal problems. Our approach to developing cultural competency involves a systems/ecological perspective, a focus on life-long professional and personal learning, and collaboration with key stakeholders and constituency groups.

Detailed information about CHFCD activities is attached.
Program Description

One of the fastest growing immigrant groups in the United States are South Asians from the Indian subcontinent and includes people from Bangladesh, Pakistan, India, and Sri Lanka. With approximately 185,000 South Asian residents, New Jersey has one of the highest proportions (2.3%) of South Asian residents in the country and has experienced a phenomenal increase (113%) between 1990 and 2000.

This conference will help raise awareness about the increased burden of chronic illness and health disparities experienced by South Asian communities for health conditions such as diabetes, cardiovascular disease, hyperlipidemia, tuberculosis, depression and cancer. By focusing on health literacy and cultural competency fields, we will educate and empower attendees from a variety of professional and consumer backgrounds to take back innovative and practical tools that can be employed in their own settings both with South Asian and other multicultural populations.

The conference will also generate recommendations and a strategic action plan for addressing health disparities and health literacy challenges in the South Asian community. We hope that the conference will also catalyze the creation of an ongoing “learning community and collaboratory” that can positively impact on clinical and preventive care, public health practice, education, research, and health care policy.

Target Audience

The conference is designed for physicians, nurses, other healthcare professionals, educators, and researchers that serve the medical and public health needs of the South Asian community; community-based organizations and government agencies that advocate for healthcare issues affecting the South Asian community; and consumers and patients who wish to better understand the dynamics of the patient-healthcare provider interaction in order to improve their health outcomes.

Learning Objectives

Upon completion of this activity, participants should be able to:

- Describe the impact of health disparities including low health literacy experienced by South Asian populations in New Jersey
- Identify and apply best and promising practices to help patients/consumers with health literacy challenges, navigate the health care system to reduce disparities, manage chronic illnesses, and support prevention activities
- Employ innovative health education strategies including multimedia, music, and mobile technologies to improve access, disease self-management, promote wellness and integrative healing, and empower patient/consumers.

Registration

Registration Fee: $75. The registration fee includes tuition, continental breakfast, lunch, and refreshment breaks, and handout materials. Participants whose registrations are received at least one week in advance of the activity will be sent a confirmation letter and directions.

Registration will only be accepted through our secure online website at: http://ccoe.umdnj.edu/SouthAsianCommunity. Minimum and maximum enrollments have been established – we urge you to register early.

Refund Policy: A full refund, less a $20 cancellation fee, will be granted if notice is received up to the date of the program. Refunds cannot be given for “no shows” or cancellations received once the program has started. For additional information on the registration process: call 973-972-4267, option 1.

Accreditation

Physicians: UMDNJ–Center for Continuing and Outreach Education is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

UMDNJ–Center for Continuing and Outreach Education designates this educational activity for a maximum of 6.75 AMA PRA Category 1 Credit(s)™. Physicians should only claim credit commensurate with the extent of their participation in the activity.

Nurses: UMDNJ-Center for Continuing and Outreach Education is an approved provider of continuing nursing education by the NJNSA, an accredited approver, by the American Nurses Credentialing Center’s Commission on Accreditation. Provider Number P173-11-09/12. Provider approval is valid through November 30, 2012.

This activity is awarded 6.75 contact hours. (60 minute CH).

Nurses should only claim those contact hours actually spent participating in the activity.

Provider approved by the California Board of Registered Nursing, Provider Number CEP 13780.

Accreditation refers to recognition of continuing nursing education activities only and does not imply the UMDNJ-Center for Continuing and Outreach Education, NJNSA, California Board of Registered Nursing or ANCC Commission on Accreditation approval or endorsement of any commercial product.

Health Educators: This program has been approved for 6.75 Category I Continuing Education Credits for CHES by the University of Medicine and Dentistry of New Jersey-School of Public Health. The UMDNJ-SPH has been designated as a provider of continuing education in health education by the National Commission on Health Education Credentialing, Inc. The approval number is 18030.

Licensed Social Workers: University Behavioral HealthCare of the University of Medicine & Dentistry of New Jersey, provider #1173, is approved as a provider for social work continuing education by the Association of Social Work Boards (ASWB) www.aswb.org, through the Approved Continuing Education (ACE) program from August 10, 2009 to August 10, 2012. University Behavioral HealthCare of the University of Medicine & Dentistry of New Jersey maintains responsibility for the program. ASWB credits are accepted by the New Jersey State Board of Social Workers. Licensed social workers participating in this course will receive 6 cultural clinical continuing education clock hours. Targeted social work practice level: Intermediate.

NOTE: Social Workers must provide their Social Work license/certification/registration number and license jurisdiction on the sign in sheet and request for certificate. Please be sure to bring this information with you to the training.
Conference Chairpersons

Sunanda Gaur, MD, Co-Director, South Asian Total Health Initiative (SATHI); Professor of Pediatrics and Director, Robert Wood Johnson AIDS Program; Director, Pediatric Clinical Research Center, UMDNJ-Robert Wood Johnson Medical School, New Brunswick, New Jersey

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Ranjitha Sandeep, Founder/Director, Yoga-Sutra for Life, Westfield, New Jersey

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Sunil J. Wimalawansa, MD, PhD, University Professor; Professor of Medicine and Physiology & Integrative Biology; Director, Osteoporosis Center, UMDNJ-Robert Wood Johnson Medical School, New Brunswick, New Jersey

The Conference Center at New Jersey Hospital Association 760 Alexander Road, Princeton, NJ 08543 l www.conferencecenternj.com/Directions.aspx

Directions and Parking www.conferencecenternj.com/Directions.aspx

For additional information or if you have special needs, contact UMDNJ-Center for Continuing & Outreach Education at: 973-972-0076 or by email at: gallsa@umdnj.edu

UMDNJ reserves the right to modify the program contents, faculty, and program activities and reserves the right to cancel the activity, if necessary.

Activity Code: 11MR08
AGENDA

7:45 am
Registration, Continental Breakfast; Exhibits

8:30 am
Opening Remarks and Conference Overview
SATHI Co-Chairs: Naveen Mehrotra, MD, MPH
Sunanda Gaur, MD

Invited Dignitaries: Peter S. Amenta, MD, PhD
Dean, UMDNJ-Robert Wood Johnson Medical School
Poonam Alaigh, MD, MSHCPM, FACP
Commissioner, New Jersey Department of Health and Senior Services
Upendra J. Chivukula
Assemblyman, New Jersey Legislature

SATHI Co-Chairs: Naveen Mehrotra, MD, MPH
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Invited Dignitaries: Peter S. Amenta, MD, PhD
Dean, UMDNJ-Robert Wood Johnson Medical School
Poonam Alaigh, MD, MSHCPM, FACP
Commissioner, New Jersey Department of Health and Senior Services
Upendra J. Chivukula
Assemblyman, New Jersey Legislature

SATHI Co-Chairs: Naveen Mehrotra, MD, MPH
Sunanda Gaur, MD

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9:15 am
Keynote Address: Addressing Health Literacy Challenges in Multicultural Communities: Best and Promising Practices
Christina Zarcadoolas, PhD

10:00 am
Break; Exhibits

10:20 am
Keynote Address: Addressing Health Disparities and Chronic Illness in South Asian Communities: What We Know and What Don’t We Know
Ranjita Misra, PhD, CHES, FMALRC

11:05 am
Panel Discussion: Interfacing Health Literacy with Selected Initiatives in Culturally Competent Health Care, Cardiovascular Health Disparities, and Provider/Consumer Health Education
Discussants: Vidya Bhushan Gupta, MD, MPH, FAAP
Namratha R. Kandula, MD, MPH
Elissa Director, MA
Moderator: Robert C. Like, MD, MS

11:50 am
Lunch; Exhibits

1:30 pm
Workshop Theme 1: Selected Health Disparities
Cancer Care and Prevention: Navigating the Healthcare System
Presenters: Kiameesha Evans, MPH, CHES
Linda Mathew, MSW, LSW, OSW-C
Biren Sarasya, MD
Facilitator: Sharad Goyal, MD

Diabetes Care and Prevention: Managing Chronic Illness
Presenters: Meena Murthy, MD
Sunil H. Parikh, MB, BS, CPM
Facilitator: Geetha R. Ghai, PhD, MBA

Tuberculosis Prevention and Control: Overcoming Stigma
Presenters: Rajita Bhavaraju, MPH, CHES
Sunanda Gaur, MD
Marybeth Caruso, RN, FN-CSA
Facilitator: Jigna Rao

3:00 pm
Break; Exhibits

3:15 pm
Workshop Theme 2: Innovative Strategies
Chronic Disease Management
Presenters: Thangamani Aravindan, MSN, RN, CCRN
Vasudev N. Makhija, MD, DFAPA
Aruna Rao, MA
Vansha Singh, MSN, APN-C
Facilitator: Aparna Kalbag, PhD

Multimedia, Music, and Mobile Technologies: Delivering Health Messages to Diverse Populations
Presenters: John D. Clarke, MD
George H. Collier PhD
Facilitator: Robert C. Like, MD, MS

Integrative Healing, Alternative Medicine, and Spirituality
Presenters: Bhaswati Bhattacharya, MPH, MD, MA
Ranjitha Sandeep
Sunil J. Wimalawansa, MD, PhD
Facilitator: Naveen Mehrotra, MD, MPH

4:45 pm
Closing Session: Addressing Health Literacy and Health Disparities Challenges in the South Asian Community: A Call to Action
Facilitators: Sunanda Gaur, MD
Naveen Mehrotra, MD, MPH
Robert C. Like, MD, MS

5:30 pm
Evaluation; Conference Adjourned

Register online: http://ccoe.umdnj.edu/SouthAsianCommunity

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The Robert Wood Johnson Foundation through its New Jersey Health Initiatives program, The Verizon Foundation, Lilly USA, LLC
ACCOMPLISHMENTS AND CURRENT ACTIVITIES OF SATHI

Community Education and Media Outreach

1) **South Asian Total Health Initiative (SATHI) website:** Development of a website with the latest and most relevant literature on health topics as they relate to the South Asian population. In addition, the website will attempt to consolidate and develop a database of health educational materials in different South Asian languages (ongoing).

2) **South Asian Disabilities Resource Center:** Development of a centralized resource center for South Asian parents dealing with autistic children. This program is being developed in collaboration with the Statewide Parent Advocacy Network (SPAN) and several prominent neurodevelopmental pediatricians: Dr. Vidya Bhushan Gupta, Dr. Uday Mehta, and Dr. Kapila Seshadri (ongoing).

3) **Cancer education program:** An educational research oriented outreach program developed in collaboration with Middlesex County Health Department (MCHD) and Bochasanwasi Shri Akshar Purushottam Swaminarayan Sanstha (BAPS Swaminarayan Temple) to raise cancer awareness on various types of cancers (breast, cervical, colorectal, skin, prostate, and oral). The first event on prostate cancer (June, 2009) successfully screened about 75 men with Digital Rectal Exams and blood Prostate Specific Antigen (PSA) test with the help of UMDNJ-Cancer Institute of New Jersey (CINJ) physicians. This program is currently being developed further with CINJ office of community outreach, MCHD, and the Indian Health Camp of New Jersey (ongoing).

4) **Disabilities in the South Asian population:** An educational media outreach to the South Asian community on disability related topics. Supported by “A Quality of Life Grant” received from the Christopher and Dana Reeve Foundation. The project is a radio campaign focused on raising awareness around disabilities issues in the South Asian population. An ongoing biweekly program which was aired on EBC 1170 AM radio, a local South Asian radio station completed in June, 2009.

5) **Ongoing attendance and organization of various health fairs in New Jersey:** SATHI has been attending various health fairs throughout New Jersey in collaboration with Edison Township Municipal Alliance, the Indian Health Camp of New Jersey, The Indian Nurses Association, BAPS, and others to provide community education on cardiovascular problems, diabetes, childhood disorders, asthma, mental illness, cancer, and other illnesses.

6) **Cancer awareness day** held on September 13, 2008 in collaboration with the Middlesex County Health Department (MCHD): a one day conference symposium held to raise health and cancer awareness in the local community. Guest speakers Jigna Rao and Dr. Sunanda Gaur provided a panel discussion on Tuberculosis.

7) **Childhood obesity in the South Asian community:** A media outreach program aired on November 29, 2007 on EBC 1170 AM Radio. Discussion focused on the nutritional aspects and prevention of obesity.

8) **Childhood obesity:** A community outreach program organized on Thursday, November 29, 2007 in collaboration with Edison Township at the Edison Council Chambers, Edison, NJ. The featured guest speaker was Fred M. Jacobs, MD, JD, commissioner of the New Jersey Department of Health and Human Services, in addition to several other nutrition and obesity experts.

9) **Participant in the South Asian Community and Disabilities Conference: Raising Awareness, Facing Challenges, Accessing Resources** on June 15, 2007 at the Hyatt, New Brunswick. The conference was organized by the UDMNJ-Elizabeth M. Boggs Center, to help organizations and agencies that provide services and support to people with...
disabilities and their families to develop a deeper and better understanding of South Asian cultural considerations and to inform members of South Asian disability communities in NJ about the resources available to them.

10) **A Celebration of Abilities**: A Pre-Conference Reception and Celebration at The Zimmerli Art Gallery, Rutgers University held on June 14, 2007 featuring Natvar Bhavsar, South Asian artist, Sujeet Desai, a musician with Downs syndrome, and Pramila Balasundaram, founder of SAMHADHAN, speaking on the artistic creativity and empowerment activities of her organization, based in New Delhi, India.

11) Domestic Violence in the South Asian Population: A **radio outreach program** which featured discussions with SAKHI, a South Asian organization that addresses issues of domestic violence (2009).

12) **Prenatal Care and Healthy Pregnancy**: A radio outreach program featuring Health Commissioner Heather Howard on issues surrounding pregnancy and prenatal care. The importance of proper prenatal care to ensure healthy pregnancy outcomes was discussed (2009).

13) In collaboration with NYMAC (New York Mid-Atlantic Consortium for genetic and newborn screening) **developed a Thalassemia outreach and education project** for South Asians (2010-2011).

14) In collaboration with the Elizabeth M. Bogg’s Center provided technical assistance in development and administration of the **Traumatic Brain Injury Needs and Resources Assessment Survey** for South Asians (2010-2011).


16) SATHI member, Jigna Rao, invited by Results, a non-profit organization, to present at **World TB Day Advocacy Tour**. This Tour was funded by a grant from the Bill and Melinda Gates Foundation (March 23-24, 2011).

17) SATHI member, Jigna Rao participated in the **TB Intensive Workshop** at The Global TB Institute of New Jersey (April 14, 2011).

Research Projects

1) **General health assessment survey of South Asians**: lead investigator, Dr. Naveen Mehrotra, co-director, SATHI. This survey is currently being implemented in the community to assess the general health practices of the South Asian community and their access to care. The survey is approved through the Institutional Review Board (IRB), UMDNJ. Data collection is completed and data analysis is in progress.

2) **Perception of mental illness research study**: lead investigator, Dr. Aparna Kalbag, post-doctoral fellow in the Office of Global Health, UMDNJ-Robert Wood Johnson Medical School, in collaboration with Dr. Sunanda Gaur, co-director of SATHI & Aruna Rao, Associate Director of the National Alliance on Mental Illness, New Jersey chapter and founder of the South Asian Mental Health Awareness in Jersey (SAMHAJ) program are conducting an ongoing, IRB-approved study of cultural differences in attitude towards and understanding of mental illness symptoms in South Asians.

3) **Breast cancer awareness and practices survey module**: lead investigator, Dr. Naveen Mehrotra in collaboration with Dr. Sharad Goyal, radiation oncologist, CINJ.

4) **Oral Cancer and oral health practices survey module**: lead investigator, Dr. Naveen Mehrotra in collaboration with Dr. Satish Mullick, Department of Dentistry, UMDNJ- Dental School, Newark.

5) **Prostate cancer perception and practices survey module**: lead investigator, Dr. Naveen Mehrotra in collaboration with Dr. Biren Saraiya, Oncologist, CINJ. This survey currently being developed with the help of UMDNJ- Internal medicine residents will assess the understanding of prostate cancer and screening practices in the South Asian men.
Medical Education Training

1) **SAMADHAN exchange program:** Developed a UMDNJ-RWJMS medical student elective program rotation at SAMADHAN (a Non-Government Organization in New Delhi, India which provides early intervention services to disabled children). Two students have participated in this elective. An NYU student went to SAMADHAN in July, 2009 and implemented a Parenting Stress Index questionnaire- a survey tool to assess the parental stress level due to a disabled child in the family. The data for this survey is currently being analyzed. A second student went to SAMADHAN in 2011 and conducted a survey of physicians’ attitudes toward patients with disabilities.

2) **Provider Training on South Asian Health:** Training of health care providers to educate them to be able to better deal with health problems in South Asians. Training sessions led by Dr. Naveen Mehrotra, were conducted for the NJ Public Health Association (December, 2009), Statewide Consortium of Cultural Competence (February, 2010), Central NJ Maternal and Child Health Consortium (March, 2010), Amerigroup Community Care (May, 2010), and Monmouth County Cancer Coalition (June, 2010).

3) **Elective Rotations arranged at Sitapur Eye Hospital (Uttar Pradesh, India), SN Medical College (Jodhpur, Rajasthan); King George Medical College (Lucknow, Uttar Pradesh, India):** Students at UMDNJ-RWJMS and other universities are eligible to take a two-to-four week rotation to get an exposure of the practice of medicine in the South Asian countries. One student took this elective in spring, 2011 and another student will be going to Jodhpur in the fall, 2011.

4) **Addressing Health Disparities and Health Literacy in the South Asian Community**- a one-day conference that took place at the **New Jersey Hospital Association** on October 9, 2010 (in collaboration with the RWJMS Center for Healthy Families and Cultural Diversity) to share information and address health disparities and health literacy challenges in the South Asian community.

**Awards/Recognition**

1) **NJ BIZ Health Care Heroes Finalist, 2009.**
2) Received proclamation from **NJ State Assembly** for conducting the “Addressing Health Disparities and Health Literacy in the South Asian Community” Conference in October, 2010.
3) **2010 Global Organization of People of Indian Origin (GOPIO) Health Council award** recipient for making a difference in the South Asian community through charity care/social service.
BRIEF DESCRIPTION AND SELECTED ACTIVITIES

The Center for Healthy Families and Cultural Diversity (CHFCD) in the Department of Family Medicine and Community Health, UMDNJ-Robert Wood Johnson Medical School was established in 1997, and is dedicated to leadership, advocacy, and excellence in promoting culturally-responsive, quality health care for diverse populations. The CHFCD recognizes that persisting racial and ethnic disparities in health and health care are major clinical, public health, and societal problems. Our approach to developing cultural competency involves a systems/ecological perspective, a focus on life-long professional and personal learning, and collaboration with key stakeholders and constituency groups.

CHFCD faculty and staff have provided multicultural education and training to residents and medical and public health students at UMDNJ-Robert Wood Johnson Medical School, as well as to numerous health care professionals in the United States and abroad. Technical assistance/consultation has also been provided to academic medical centers, hospitals, ambulatory care facilities, managed care plans, community organizations, governmental agencies, and medical communications and pharmaceutical companies. Topic areas addressed include: addressing health disparities; developing clinical and organizational cultural competence; caring for patients with limited English proficiency and health literacy challenges; participatory quality improvement; and cross-cultural health promotion and disease prevention.

Selected examples of major cross-cultural training and research initiatives the CHFCD has actively participated in include:

- Society of Teachers of Family Medicine's "Recommended Core Curriculum Guidelines for Culturally Sensitive and Competent Health Care" (http://www.stfm.org/corep.html)
- Office of Minority Health’s “A Physician’s Practical Guide to Culturally Competent Care” (http://cccm.thinkculturalhealth.org)
- Institute for Healthcare Improvement/HRSA National Health Disparities Collaboratives "Cultural Competence in the Clinical Care of Patients with Diabetes and Cardiovascular Disease Curriculum"
- Transforming the Face of Health Professions Through Cultural & Linguistic Competence Education: The Role of the HRSA Centers of Excellence (http://www.hrsa.gov/CulturalCompetence/research.html)
- HRSA and OMH "Cross-Cultural Communication in Health Care: Building Organizational Capacity" National Satellite Educational Broadcast (http://www.hrsa.gov/reimbursement/broadcast/default.htm)
- California Endowment "Principles and Recommended Standards for Cultural Competence Education of Health Care Professionals"/Cultures in the Clinic project (http://www.calendow.org/uploadedFiles/principles_standards_cultural_competence.pdf)
- Georgetown University National Center for Cultural Competence, "Cultural Competence Health Practitioner Assessment Instrument" and Cultural and Linguistic Competency Policy Assessment” projects (http://www11.georgetown.edu/research/guechd/ncc)
- UMDNJ/Robert Wood Johnson Medical School (RWJMS) Four National Conferences on Culturally Competent Care (http://rwjms.umdnj.edu/departments_institutes/family_medicine/chfcd/outreach/conferences.html)
- UMDNJ Continuing Medical Education Multicultural Education Programs - "REACH: Realizing Equity Across Cultures in Healthcare" and "Building Cultural Competency in Clinical Practice" (Eden Communications/Pfizer)
- The Praxis Partnership -- Division of CME, University of Alabama School of Medicine; Division of CME, Vanderbilt University School of Medicine; and Nexus Communications, Inc. “Initiative for Decreasing Disparities in Depression (I3D)” (project supported by Wyeth Pharmaceuticals) (http://www.i-3d.org)
- American Medical Student Association’s (AMSA) Achieving Diversity in Dentistry and Medicine through Implementing Cultural Competency Curricular Guidelines for Medical Schools Program, “Transforming the Curriculum at Robert Wood Johnson Medical School: Educating Students and Faculty about Culturally Competent Patient Centered Care” grant
- Montana State University – Bozeman/Health and Human Development. “Messengers for Health grant” (Indian Health Service health care providers)
- Bildner Family Foundation New Jersey Campus Diversity Initiative - "Developing Cultural Competency at UMDNJ”
- Northeast Consortium on Cross Cultural Medical Cultural Medical Education and Practice
- American Journal of Multicultural Medicine Series (Liberty Communications Network/Cardinal Health)
- Diversity in Health and Care journal, Editorial Advisory Board
- Aetna Foundation-funded research project, "Assessing the Impact of Cultural Competency Training Using Participatory Quality Improvement Methods" (http://rwjms.umdnj.edu/departments_institutes/family_medicine/chfcd/grants_projects/aetna.html)
- South Asian Total Health Initiative (SATHI), Department of Pediatrics, UMDNJ-Robert Wood Johnson Medical School
- American College of Cardiology CREDO (Coalition to Reduce Disparities in Cardiovascular Outcomes) Initiative (http://www.cardiosource.org/ACC/credo1.aspx)
- American Heart Association Cultural Competency Initiative
- European Union’s Migrant–Friendly Hospitals Initiative to Promote the Health and Health Literacy of Migrants and Ethnic Minorities and Amsterdam Declaration (http://www.mfh-eu.net)

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