BACKGROUND AND HISTORY OF ASIAN AMERICAN NATIVE HAWAIIAN & PACIFIC ISLANDER DIABETES COALITION

In September 2011, the National Council of Asian Pacific Islander Physicians (NCAPIP), along with the Joslin Diabetes Center Asian American Diabetes Initiative (AADI) at Harvard Medical School, American Diabetes Association (ADA), University of Hawaii John A. Burns School of Medicine, Association of Asian Pacific Community Health Organizations (AAPCHO), Waianae Coast Community Health Center, Chinese American Medical Society of New York (CAMS), Empowering Pacific Islander Communities (EPIC), and California Medical Association Foundation Network of Ethnic Physician Organizations, organized a historic “state of the science” national conference on diabetes in the Asian American, Native Hawaiian, and Pacific Islander (AANHPI) populations and communities in Honolulu, HI. ¹ The summit brought together leading researchers, physician leaders, diabetes educators, and community-based diabetes program managers to discuss the epidemiology, treatment and management, and prevention and education interventions regarding diabetes among AANHPIs.

The participants had the following recommendations for action:

Collect More Data on Diabetes in Asian Americans, Native Hawaiians, and Pacific Islanders

+ Support funding for more research on diabetes specific to Asian Americans, Native Hawaiians, and Pacific Islanders, especially about Type 1 diabetes and

¹ http://s3.amazonaws.com/NCAPIPportalDocfiles/compendium_Summary_high5.pdf
for subgroups, including Native Hawaiians, Pacific Islanders, Filipinos, South Asians

+ Support the oversampling of Asian Americans in the National Health and Nutrition Examination Survey (NHANES)

+ Support the oversampling of Native Hawaiians and Pacific Islanders in the NHANES

+ Use and support more community-based participatory research about diabetes in Asian American, Native Hawaiian, and Pacific Islander communities

**Provide Culturally Appropriate and Community-Driven Diabetes Prevention Education and Interventions for Asian American, Native Hawaiian, and Pacific Islander Communities**

+ Learn from experiences in Asian American, Native Hawaiian, and Pacific Islander communities about diabetes prevention education and interventions

+ Ensure that diabetes prevention education programs for Asian American, Native Hawaiian, and Pacific Islander communities are culturally appropriate, use patient-centered language, and are accessible to the members of the community in need

+ Involve Asian American, Native Hawaiian, and Pacific Islander community participants in the design, implementation, and evaluation of diabetes prevention education and interventions

**Develop Clinical Guidelines to Improve Care for Asian Americans, Native Hawaiians, and Pacific Islanders with Diabetes**

+ Review current recommendations and clinical guidelines on diabetes care for their relevance to Asian Americans, Native Hawaiians, and Pacific Islanders

+ Develop Asian American, Native Hawaiian, and Pacific Islander population-specific guidelines for treatment and management of diabetes

**Develop Partnerships to Improve the Prevention of Diabetes and the Care of Asian Americans, Native Hawaiians, and Pacific Islanders with Diabetes**

+ Support more sharing of knowledge and experiences among Asian American, Native Hawaiian, and Pacific Islander communities, health care providers, researchers, government health officials, pharmaceutical industry, employers, and other stakeholders

+ Work to better understand and address the social determinants of health in Asian American, Native Hawaiian and Pacific Islander communities

+ Continue the National Asian American, Native Hawaiian, and Pacific Islander
Diabetes Coalition as an ongoing effort

After the conference, NCAPIP and its partners formed the AANHPI Diabetes Coalition to advance the study and treatment of diabetes in AANHPI populations and communities, in order to effectively prevent and treat this serious disease. The Coalition partners agreed to work together to:

● Bring together the stakeholders, including physicians and other health care providers, health educators, researchers, community-based organizations, patient and consumer organizations, health departments, and the pharmaceutical industry
● Increase awareness about the diabetes disparity in AANHPI populations and communities
● Support research on appropriate clinical and community interventions to effectively prevent and treat diabetes in AANHPI populations and communities
● Advocate for more resources from government and the private sector to focus on diabetes in AANHPI populations and communities.²

An initial, important outcome from the unprecedented collaborations at the first conference were two co-authored articles describing the state of the science about diabetes in AANHPI populations.³⁴

In May 2012, NCAPIP and the AANHPI Diabetes Coalition organized a second conference in Arlington, VA. At the conference, a set of recommendations was discussed and finalized to develop clinical management guidelines for various AANHPI populations, to gather definitive data to guide management, and to develop tailored community interventions. The following 3x3 Action Steps were adopted by the AANHPI Diabetes Coalition:⁵

Provisional Clinical Management Guidelines for Various Asian Americans

+ Asian Pacific American Diabetes Action Council (APADAC) and National Adult Strategies Committee will work with the guideline committee within the American Diabetes Association (ADA) regarding the Asian American BMI guideline

+ Create a letter as the AANHPI Diabetes Coalition, supported/signed by the members to support APADAC and National Adult Strategies Committee’s efforts

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² [http://www.ncapip.org/diabetes/page64/](http://www.ncapip.org/diabetes/page64/)
+ Additional follow-up with ADA, Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH) regarding Centers for Medicare and Medicaid Services (CMS) reimbursement for obesity prevention education (and obesity surgery) needing to include lower BMI cutoff for Asian Americans

**Gathering Definitive Data for AANHPI to Guide Future Management**
+ Work with CDC to do meta-analysis using existing data regarding AANHPIs

+ Work with NIH National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK) to increase the number of Requests for Applications targeting AANHPIs

+ Work with organizations such as Kaiser Permanente and Harvard Pilgrim Health Care to institute Asian American guidelines and collect data to see the impact and benefits of using these data

**Develop and Implement Community Tailored Interventions**
+ Create brochures/materials based on the two papers published in *Diabetes Care*

+ Disseminate to providers (physicians and educators) through working with our existing network such as the ADA and American Association of Clinical Endocrinologists (AACE)

+ Develop a long-term plan (target providers first, then general public, etc.)

In May 2013, NCAPiP and the AANHPI Diabetes Coalition organized a third conference in Washington, DC to further implement the Action Plan. At this conference, the Pacific Jurisdiction health care system assessment, with a focus on chronic diseases and diabetes, was presented. In Pacific Islander populations, adherence to diabetes treatment plans is significantly worse than the U.S. general population, resulting from many factors including the patients, providers, health care system, and community.

As a result of the conference, the AANHPI Diabetes Coalition also engaged in a formal dialogue with the National Institute of Diabetes and Digestive and Kidney Diseases (NIH-NIDDK) on a research agenda, and presented a written request to the NIDDK Director “for greater understanding and treatments of diabetes and its complications in the AANHPI populations.”

It is well-accepted that weight gain in adult life results in an increasing Body Mass Index (BMI) and is associated with increased morbidity, including diabetes, and mortality. However, the AANHPI Diabetes Coalition believes that the BMI cut-off points for overweight and obesity currently used for the general U.S. population should not be applied in isolation, but in combination with other risk factors.
On the basis of available data in Asia, the World Health Organization (WHO) has concluded that Asians generally have a higher percentage of body fat than Whites of the same age, sex, and BMI, and that their proportion with risk factors for type 2 diabetes and cardiovascular disease is substantial, even below the existing BMI cut-off point of 25 kg/m² for overweight and 30 kg/m² for obesity.  

The purpose of a BMI cut-off point is to identify, within each population, those individuals with a high risk of a disease state that warrants a public health or clinical intervention. Using lower BMI cut-off points for action on overweight and obesity among Asian Americans would increase their prevalence rates overnight and, therefore, increase governmental and public awareness. Such a change would require public health policies and clinical management guidelines to be changed, and could lead to increased costs in the short term (more treatment at lower BMI thresholds), but cost savings in the long term (less disease and co-morbidities).

In October 2013, the release of initial data from the 2011-2012 Asian American oversampling of the National Health and Nutrition Examination Survey (NHANES) prompted the AANHPI Diabetes Coalition to work with the Centers for Disease Control and Prevention (CDC) to both disseminate and respond to the data briefs. Another data brief released in January 2014 reported that Asian Americans have a disproportionally lower level of high BMIs, with only 39% above BMI of 25 compared to non-Hispanic White, Black and Hispanic adults (67%, 77% and 79% respectively). These data give the false impression that obesity and its related diseases are less of a problem in the Asian American population and might result in large numbers of at-risk Asian Americans not getting the appropriate screening, prevention, or treatment for obesity and obesity-related diseases.

On a recommendation by the AANHPI Diabetes Coalition, CDC did include the following cautionary note on pages 5-6 of the January 2014 Data Brief:

"BMI is widely used as a measure of body fat. However, at a given BMI level, body fat may vary by sex, age, and race and Hispanic origin. In particular, at a given BMI, Asian adults may have more body fat than white adults. Also, morbidity and mortality risk may be influenced by body composition and fat distribution in a manner that is not completely captured by BMI."
The NHANES data also showed that Asian American men have much higher prevalence of low levels of HDL (<40) than Asian American women, compared to other ethnic groups, and that foreign-born Asian Americans have much lower HDL levels than U.S.-born Asian Americans. Anticipated additional data regarding Hg-A1C in Asian Americans compared with other racial and ethnic groups would advance the understanding and potential development of surrogate markers for increased risks of cardiovascular disease and insulin resistance, diabetes and metabolic syndrome within AANHPIs.

NCAPIP and the AANHPI Diabetes then organized a fourth conference in May 2014 in San Francisco, CA, with the theme: Deepening Knowledge: Effective Treatment and Management. The objectives of the conference were to further deepen the knowledge of diabetes in the AANHPI populations and communities, and to translate this knowledge and existing data into concrete policies for effective treatment and management of the disease.

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Diabetes in Asian Americans, Native Hawaiians, and Pacific Islanders
Deepening Knowledge: Effective Treatment and Management

May 2, 2014

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Opening Remarks
George L. King, MD
Joslin Diabetes Center, Harvard Medical School
Co-Chair, Asian American Native Hawaiian Pacific Islander Diabetes Coalition

We now know that Asian Americans are at risk for diabetes even at Body Mass Index (BMI) cut-points below 25. There could be up to 5 million individuals, including many Asian Americans, who have diabetes but are not obese. The information we learn about Asian Americans and diabetes will be applicable to other populations who have diabetes but are not obese.

We have very little data about Type 1 diabetes among Asian Americans, except that it is rare. This lower prevalence also is worthy of further research to understand Type 1 diabetes.

Meanwhile, there is an increasing prevalence of diabetes in Asia; the rate in China is now 11.6%. The diabetes prevalence rate in Hong Kong and Singapore also are 12%. In ten years, half of the diabetes cases in the world will be in Asia. We need to look globally when considering how diabetes impacts Asian Americans.

Going forward, we need to continue to raise awareness about diabetes among Asian Americans, Native Hawaiians, and Pacific Islanders, and to create and provide tools
for prevention. We also need to improve diabetes care, and reduce diabetes-related disparities for Asian Americans, Native Hawaiians, and Pacific Islanders. This includes more education for providers and reimbursements for early interventions, even at lower BMI cut-points. There are over 20 Asian American subgroups. While some interventions such as increased physical activity, exercise, changes in diet work across all populations, we need to focus on the cultural background and lifestyle of our patients to provide the most effective care. Finally, we need further research to find specific solutions for diabetes among Asian Americans, Native Hawaiians, and Pacific Islanders, funded by the National Institutes of Health, Centers for Disease Control and Prevention, Centers for Medicare and Medicaid, American Diabetes Association, and other funders.

Reference
King, GL., Stopping Diabetes in the Asian American Community
http://diabetesstopshere.org/2014/05/01/stopping-diabetes-in-the-asian-american-community/

S. Floyd Mori
Asian Pacific American Institute for Congressional Studies

Doctors are one of the most trusted professions in the nation; we literally put our lives in their hands. Doctors should utilize their knowledge and position as trusted individuals to get involved in issues such as diabetes. As a former elected official (mayor and state legislator) and now working closely with the Congressional Asian Pacific American Caucus, I know that politics has a lot to do with health, especially what gets funded. As doctors, you should get involved to advocate for the needs of the communities served.

Keynote Address
Kenneth P. Moritsugu, MD, MPH
Former Acting U.S. Surgeon General

10 million individuals in the U.S. have diabetes but another 7 million are undiagnosed. And everyone who has diabetes has family members and loved ones who also are affected by the disease so ultimately, everyone is affected by diabetes.

There continues to the limited data about Asian Americans and diabetes, with data often reported only for Whites, Blacks, and Hispanics. But we know that diabetes is a growing epidemic that disproportionately affects racial and ethnic minorities. There is a lack of awareness among Asian Americans, Native Hawaiians, and Pacific Islanders about the risk of developing diabetes. There is a misconception that being “skinny” equals a low risk for diabetes. And since many Asian Americans are “skinny”, it is assumed that Asian Americans are healthy and not at risk for diabetes. We now know that Asian Americans who are not obese are at risk for diabetes. Yet diabetes education, counseling, and treatment often are not available because it is assumed that Asians Americans are not at risk for diabetes. This is a form of discrimination against Asian Americans.
We need to know the science and the facts about diabetes among communities such as Asian Americans. Too often we focus on the “what” in science and evidence, without giving enough attention to the “how”, how that science will be translated into benefits for individuals. One size does not fit all; we need to tailor medicine to fit the needs of individuals and communities. We need disaggregated data because one “Asian” is not the same as another “Asian”. The diversity of Asian Americans, Native Hawaiians, and Pacific Islanders is especially important to understand.

We need personalized medicine, not cohort medicine, especially for communities of color. We need to shift from intervention medicine” to preventive medicine, including primary, secondary, and tertiary prevention; we need to shift our focus from acute care to chronic care.

An integral role that physicians must play is that of a communicator, rather than remaining siloed on our offices, hospitals, and academic institutions without effectively communicating the best science available to those we serve. Rather than pointing our fingers at patients, we need to address health literacy and communicate so that patients can hear, understand, and embrace our health messages and put them into action. There is no way that a doctor can always be present in the life of patient to tell them what to do; we need to involve patients in their health care, to motivate them to share responsibility for their health and well-being. The new role of physicians will be as partners with patients to share information, as partners with other health care providers to coordinate care, as partners with others in the community to address the social determinants of health. We need to put patients at the center of everything we do.

Reference
Moritsugu, K. Diabetes: A Global Crisis, A Challenge for AANHPIs
https://lillypad.lilly.com/entry.php?e=4142

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Deepening Knowledge by Oversampling Asian Americans
Wilfred Y. Fujimoto, MD
University of Washington

While the common risk factors for diabetes are older age, family history of diabetes, previous gestational diabetes, physical inactivity, being overweight or obese, hypertension, dyslipidemia (high triglycerides, high cholesterol, and/or low HDL-cholesterol), we are learning more and more about diabetes among Asian Americans, Native Hawaiians, and Pacific Islanders. Native Hawaiians have the highest prevalence of diabetes in Hawaii. The higher prevalence of diabetes among Native Hawaiians, Filipinos, South Asians cannot be explained by the usual correlation with being overweight or obese. Diabetes among these populations often occurs at lower BMI cut-points. Many Asian Americans have higher visceral and subcutaneous fat levels that corresponds with higher risk for diabetes.
References


Survey Data from the Centers for Disease Control and Prevention: Oversampling of Asians
Judith A. McDivitt, PhD
National Diabetes Education Program, Centers for Disease Control and Prevention

The National Health and Nutrition Examination Survey (NHANES) is a continuous Centers for Disease Control and Prevention survey that also includes a physical examination and lab tests, with 5,000 respondents each year. In past annual cycles, there has been oversampling of Asians, among other populations. Some survey materials are available in Chinese, Korean, Vietnamese, and Hindi and surveyors receive cultural competency training.

In the 2011-2012 cycle, 754 Asians were included in the total sampling of 9,756 adults. Data from the 2013-2014 cycle will be needed to ensure acceptable statistical reliability of the detailed data from the Asian sampling (with approximately 1,500 combined Asian respondents). The was a 10.2% prevalence rate of diabetes among the Asian respondents in the 2011-2012 cycle.

The National Health Interview Survey (NHIS) is another Centers for Disease Control survey of over 39,500 households each year. This survey is conducted by telephone with selected households. Beginning in 1996, there has been an oversampling of Asians. In 2011, there were 7,569 Asians sampled, including 1,689 Filipinos, 1,509 Chinese, and 1,297 Asian Indians.
Beginning in 2014, there will be the first oversampling of Native Hawaiian and Other Pacific Islander households in NHIS, with a goal of sampling 4,000. Data from this Native Hawaiian and Pacific Islander oversampling will be available in mid-2015.

References
Main NHANES page: http://www.cdc.gov/nchs/nhanes.htm
Main NHIS page: http://www.cdc.gov/nchs/nhis.htm

Addressing Diabetes Among Hmong Adults
Moon S. Chen, Jr., PhD, MPH
University of California, Davis, Comprehensive Cancer Center
Kendra Thao
Hmong Women’s Heritage Association

The Hmong were the fastest growing population in Sacramento from 1990-2000, now totaling nearly 30,000 residents. It is the third largest Hmong community in the U.S. Out of that community, 31% are below the federal poverty level, only 14% have a bachelor’s degree or higher education, and 46% are limited English proficient.
The only two previously published studies about diabetes in the Hmong community estimated a prevalence rate between 16% and 40%, and at 32%, much higher than among the overall U.S. population. The Thousand Asian American Study in Sacramento (2012-2013) reported a diabetes prevalence rate among Hmong of 14.5%, with 33.5% at increased risk for diabetes.

The Hmong view diabetes as a Western disease, which they understand as a soul trying to return home, causing an imbalance in the body. A Hmong Community Health Navigators program was begun in 2010 to assist Hmong community members diagnosed with diabetes, hypertension, and cancer to better navigate health care systems and access needed resources. Language, cultural, socioeconomic, and systemic (e.g., lack of culturally and linguistically appropriate health care workforce) barriers to improved diabetes management were identified, requiring a “whole health” approach to providing the needed primary medical care, social, behavioral, and spiritual services to support the community members with diabetes. The diabetes self-management program including a strength-based assessment; support for regular A1c, blood pressure, and cholesterol testing; and self-advocacy skills-building. Community-based organizations have the trust of the community to implement these health programs.

References
Her C, Mundt M. Risk prevalence for type 2 diabetes mellitus in adult Hmong in Wisconsin: A pilot study. WMJ. (2005);104(5):70-77


Diabetes in South Asians: Findings from the MASALA Study
Alka Kanaya, MD, PhD
University of California San Francisco School of Medicine

There are over 3.4 South Asians in the U.S. (from Bangladesh, Bhutan, India, Nepal, Pakistan, and Sri Lanka). The prevalence of diabetes among South Asians in the U.S. is 17.4%.
The Mediators of Atherosclerosis in South Asians Living in the America (MASALA) Study uses a similar design and measures from the national MESA study (with over 6,800 White, African American, Latino and Chinese American participants from 2000-2007). There are 900 South Asian participants in the MASALA study, enrolled through the University of California San Francisco and Northwestern University. While the South Asians in the MASALA study were less likely to be smokers and drank less alcohol compared to the participants in the MESA study, the South Asians had significantly lower levels of exercise and physical activity.

The adjusted prevalence of diabetes among the South Asians in the MASALA study was 26.4%, significantly higher than the ethnic populations in the MESA study, after adjusting for all known risk factors associated with diabetes.
## Adjusted prevalence

<table>
<thead>
<tr>
<th></th>
<th>South Asian n=799</th>
<th>White n=2,611</th>
<th>African American n=1,879</th>
<th>Latino n=1,493</th>
<th>Chinese American n=801</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Crude prevalence, %</strong></td>
<td>21.1 (18.3-24.0)</td>
<td>6.0* (5.1-7.0)</td>
<td>17.7** (15.9-19.4)</td>
<td>17.7** (15.7-19.6)</td>
<td>13.1* (10.8-15.4)</td>
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<tr>
<td><strong>Age, sex and site-adjusted</strong></td>
<td>23.2 (18.3-28.1)</td>
<td>5.9* (4.9-6.8)</td>
<td>18.0** (15.9-20.0)</td>
<td>17.0** (14.9-19.3)</td>
<td>13.2* (10.6-15.8)</td>
</tr>
<tr>
<td><strong>Fully adjusted†</strong></td>
<td>26.7 (21.2-32.3)</td>
<td>6.3* (5.3-7.3)</td>
<td>16.4** (14.5-18.3)</td>
<td>14.4* (12.6-16.3)</td>
<td>16.0* (12.9-19.1)</td>
</tr>
</tbody>
</table>

* p<0.05; **p<0.001 compared to South Asians
† adjusted for age, sex, clinical site, education, family income, smoking, alcohol use, exercise, BMI, waist circumference, HDL, triglycerides, hypertension, and fasting insulin

### References


**Type 2 Diabetes Prevalence: University of California San Diego Filipino Health Study**

Maria Rosario (Happy) G. Araneta, PhD
*University of California San Diego School of Medicine*

According to the American Community Survey, there were over 3.4 million Filipinos in the United States in 2011. Data from the Diabetes Study of northern California (DISTANCE) in 2010 showed Type 2 diabetes prevalence rates of 18.3% for Pacific Islanders, 16.1% for Filipinos, and 15.9% for South Asians, exceeding the prevalence among African-Americans, Latinos, and Native Americans, groups traditionally perceived to be at highest risk for type 2 diabetes. That data set also showed gestational diabetes prevalence of 11.1% among Asian Indian women, 9.6% among Filipina women, and 8.8% among Southeast Asian women exceeding the prevalence of white women.

The University of California San Diego Filipino Women’s Health Study began in 1995, enrolling 453 Filipinas ranging from 40 to 86 years old. Almost all the women (99%) were born in the Philippines, with both very recent immigrants and those who had lived in the U.S. for up to nearly five decades. 36.4% of the Filipina women had Type 2 diabetes, even though only 8.8% had BMI >30 kg/m². And the Filipina women had greater (69.1 cm³) visceral adipose tissue (VAT), compared to white women (62.3 cm³) and African American women (57.5 cm³) in parallel study cohorts. Most significantly, Filipina women with “normal weight” (BMI <23 kg/m²) had greater VAT (53.8 cm³) and higher prevalence of Type 2 diabetes (21.6%), compared to white women and African American women with “normal weight” (BMI <25 kg/m²).

The study also measured levels of adiponectin hormone, which is decreased with greater VAT. Lower levels of adiponectin is associated with higher rates of insulin resistance and Type 2 diabetes. The study found Filipina women had the lowest levels of adiponectin (ug/ml). Among women with the lowest level of adiponectin (<5.4 ug/ml), 51% of the Filipina women had Type 2 diabetes, compared to 17% among Filipinas with the highest adiponectin concentrations (>=9.3 ug/ml) 24% of African American women. Data from the Philippine National Nutrition and Health Survey in 2003-2004 also reported high prevalence of Type 2 diabetes (44%) among Filipinos with the lowest levels of adiponectin (<7.2 ug/ml).

Only 13.4% of the Filipina women had previously been diagnosed with Type 2 diabetes before study enrollment. Another 5.7% were newly diagnosed with a fasting
glucose test. However, another 13.4% were additionally diagnosed with a two hour oral glucose tolerance test. Another 32% had pre-diabetes.

In another study, screening using HbA1c measurements identified 8.9% new type 2 diabetes diagnoses among Filipino, Native Hawaiian, and Japanese adults compared to a prevalence of 15.5% by 2-hour oral glucose tolerance test (OGTT). This implies that if diabetes screening is limited to just HbA1C or a fasting plasma glucose test, almost half (47%) of Asian-Americans with type 2 diabetes might remain undiagnosed without an OGTT test.

References


**Commentator**
Jane Chiang, MD
American Diabetes Association

Dr. Chiang identified herself as a Korean American who is pre-diabetic, even though she has a BMI of 21. She shared her experiences as a medical student and now at the American Diabetes Association. There is room for change. There are few care recommendations specific to Asian Americans. We need more information about Asian Americans and diabetes.

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**Lunch Discussion: Increasing Diversity in Clinical Trials**
Salvatore Alesci, MD, PhD
PhRMA

By 2020, 40% of the U.S. population will be racial and ethnic minorities. There are scientific, regulatory, ethical and operational reasons for increasing diversity in clinical trials. Currently, clinical trials are highly localized, in temporary and often siloed networks. There often is no capacity to reach and include populations that might have unique risks for disease. Two-thirds of Americans report that they would be likely to participate in a clinical trial if recommended by their health care providers. Yet only 22% report ever being asked by their physician to participate in a clinical trial.

PhRMA is working on raising awareness of the importance of participation in clinical trials, developing a competent clinical trial workforce, and building connectivity among stakeholders (patients, sponsors, investigators, healthcare providers, their institutions and advocacy organizations) in the clinical trial ecosystem.

“I’m In” is a patient-centered community-focused campaign designed to improve health by increasing clinical trial participation among traditionally underrepresented
populations, including individuals of varied races and ethnicities. The campaign seeks to engage patient advocacy organizations, provider advocacy groups, clinical trials sponsors and researchers, pharmaceutical companies, and elected officials through digital media, media relations, and advocacy approaches.

Reference
https://www.joinimin.org/SitePages/diversity-in-clinical-trials.aspx

Gary Puckerin, PhD
National Minority Quality Forum

The National Minority Quality Forum is a research and education organization whose mission is to strengthen the ability of communities and policymakers to eliminate the disproportionate burden of premature death and preventable illness in special populations through the use of evidence-based, data-driven initiatives. The organization has developed a comprehensive database comprised of over 800 million patient records to define disease prevalence, costs, and outcomes at the zip code level for racial and ethnic minority populations. For example, while the prevalence of diabetes among Asian Americans nationally might be lower than other groups, it is higher in San Francisco, where there is a higher Asian American population.

The National Minority Quality Forum is working with the “I’m In” campaign to develop a Clinical Trial Engagement Network that includes a national research directory of stakeholders, an investigator registry, and a patient registry for those interested in participating in clinical trials. The network also will have Clinical Trial Engagement Centers, which are points of care located in diverse communities with access to large populations underrepresented in clinical trials. Physicians also need to be educated that they can be reimbursed for counseling their patients about clinical trials.

Gordon Fung, MD, PhD, MPH
University of California San Francisco School of Medicine

In the past, some doctors did not want to accept Chinese American patients for bypass surgeries because they believed that these patients have more advanced heart disease and would have more complications. On the other hand, there was a case in which Dr. Fung was told that a Chinese American woman had refused cardiovascular surgery when in fact no one had communicated her cardiovascular issues and treatment options to her in her Chinese dialect so that she could understand and make an informed decision. When the communication was provided in her dialect, she opted for surgery and had a good recovery.

Many diseases and conditions are linked. 20% of the patients who come into the hospital with a heart attack have early signs of diabetes. Among Asian American populations, stroke is more prevalent than coronary heart disease. 50% of those who have a stroke also have diabetes.

Informed consent is vital; physicians must note that a clinical trial is entirely voluntary and explain all the risks.
George L. King, MD  
Joslin Diabetes Center, Harvard Medical School  

Physiological and genetic differences among individuals affect pathogenesis of disease, and the pharmacokinetics, metabolism, and side effects of treatments. There also are cultural and environmental differences in how treatment is received, including stress, socio-political factors, and diet. For example, for patients with diabetes being treated with an insulin lispro mix 50/50 three times daily (LMTID), hemoglobin A1c outcomes are comparable across patient groups. However, during treatment with LMTID, Asian patients experienced higher incidence and rate of severe hypoglycemia than White patients.

The FDA has used race-specific information from clinical trials in its drug safety information. For example, in 2005, the FDA noted results from a Phase 4 pharmacokinetic study in Asian-Americans to highlight important information on the safe use of Crestor (rosuvastatin) and to reduce the risk for serious muscle toxicity (myopathy/ rhabdomyolysis). Clinical treatment trials in the U.S. need to include adequate number of minorities which can provide guidelines for the use of a drug or treatment in each significant minority populations.

References  

U.S. Food and Drug Administration, Public Health Advisory for Crestor (rosuvastatin), March 2, 2005,, accessed at:  

U.S. Food and Drug Administration, Crestor (rosuvastatin calcium) Prescribing Information (March 2005), accessed at:  
http://www.accessdata.fda.gov/drugsatfda_docs/label/2005/21366slr005lbl.pdf

Moon S. Chen, Jr., PhD, MPH  
University of California, Davis, Comprehensive Cancer Center  

Clinical trials advance the field of our knowledge about diseases and treatments and participants in clinical trials get better care than those who are not participants. For Asian Americans, the burden of diseases such as cancer are unique, unusual, and often unnecessary (preventable). Yet out of 10,000 National Cancer Institute-sponsored clinical trials, less than 150 focused on racial and ethnic minority patients, none focused on Asian Americans and only one on Pacific Islanders. Only 1.7% of all the adults in clinical trials are Asian American. Asian American, Native Hawaiian, and Pacific Islander participation in clinical trials can be increased when their doctors recommend participation, when trust in the benefits of the clinical trial is earned, and when there is cultural sensitivity and linguistic competence.

Ho Luong Tran, MD, MPH  
National Council of Asian Pacific Islander Physicians
These are important conversations, including how to provide Continuing Medical Education (CME) credits for physicians to learn more about clinical trials. More also can be done to improve access to information to physicians about clinical trials through technology. NCAPIP has established a website portal that can be used for followup discussions.

TRANSLATING DATA INTO COMMUNITY AND PATIENT BENEFIT

Jonca Bull, MD
Office of Minority Health, Food and Drug Administration

Part of the mission of the Food and Drug Administration (FDA) is effective communication to the public about approved drugs and about drug safety. It is vital to use plain language and address health literacy in health communications. The agency has a language access plan, with consumer materials and press releases translated into multiple languages. For example, FDA’s consumer diabetes information for women is available in Bengali, Chamorro, Urdu, Cambodian, Chinese, Samoan, Japanese, Korean, Laotian, Taglish, Thai, Tongan, and Vietnamese. The FDA wants to become more of a health information provider of choice for the American public.

The FDA also is using social media as part of the agency’s public communications. The FDA has regulatory authority over mobile medical apps. There will likely be many mobile medical apps relevant for diabetes.

The FDA also is working to report and improve the level of participation of racial and ethnic minorities in clinical trials. The most important factors in clinical trial recruitment are usually speed and cost where patients can be accrued the easiest. Inclusion and exclusion criteria also can both decrease and increase the level of participation of racial and ethnic minorities in clinical trials.

To advocate effectively for specific populations such as Asian Americans, Native Hawaiians, and Pacific Islanders, community representatives can participate in FDA advisory committees- especially important in the open public hearing, to ensure their diverse perspectives are shared. Scientists and consumers from diverse communities are also encouraged to apply for participation as member of FDA advisory committees.

REFERENCES
The American Diabetes Association (ADA) has four diabetes action councils focused on racial and ethnic disparities, including an Asian Pacific Islander Diabetes Action Council. The ADA is increasing its advocacy capacity to inform policymakers about diabetes disparities, including support for H.R.3322, the Eliminating Disparities in Diabetes Prevention, Access, and Care Act, re-introduced in October 2013. The ADA also is supporting diabetes research in diverse communities.

Patients can be effective advocates for themselves when they ask their health care providers questions. The ADA is using social media to reach and engage community members directly, including asking them to advocate with their legislators on diabetes issues.

References


Amy O’Connor
Lilly

The key to effective communication is the right message to the right person at the right time with the right call to action. Lilly is using digital and social media to communicate its messages to improve health and influence public policy. 88% of caregivers go online for information to help them care for their loved ones. Nurses are highly engaged in social media and are important recipients and senders of health communications. Data also shows that 60% of legislators learn about issues online, and that one-third change their mind based on the online information. Asian Americans have particularly high rates of utilization of digital and social media, with
87% connected to the internet and 65% using social media (the highest among any racial or ethnic group).

**Winston Wong, MD, MS**  
Kaiser Permanente

17%, or 1.2 million, of Kaiser Permanente’s 9.3 million members are Asian American and Pacific Islander. While “Asian American and Pacific Islander” is useful as a political term for policy advocacy, in health care, it is almost useless term for an aggregated group when it is understanding the subpopulations that matter.

Data and information about prevalence, processes, and treatment for diseases such as diabetes in specific populations is essential for system changes. This supports improved patient-physician interactions. We should also monitor quality performance by race and ethnicity using electronic health records. For example, Kaiser has analyzed its own data to learn that co-payments are a barrier for many of its African American members in sustaining their adherence to prescribed medications.

Kaiser is one model of accountable care type organizations responsible for managing large populations. The interface between patients and the health care delivery system is changing. There will be more virtual visits rather than traditional office visits. At Kaiser, 30% of interactions between providers and patients are by email. These additional types of interaction can support improved education about diabetes risk, education, treatment. Health information should not just come from doctors but from all members of the health care team. The younger generation (millenials) have different ideas about who is credible, are more likely to “crowdsource” an answer from their social media networks than pay attention of the academic or other credentials of the messenger. This is an opportunity to educate and engage a new generation about diabetes in our communities.

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**Diabetes in the U.S. Pacific Islands**  
Nia Aitaoto, PhD, MS, MPH  
Faith in Action Research Alliance

**Raynald Samoa, MD**  
City of Hope Medical Center

The reported prevalence of diabetes in the U.S.-associated Pacific Islands are as high as 47% in American Samoa, 39% in the Republic of Palau, 30% in the Republic of Marshall Islands and 24% in the Federated States of Micronesia.
Other surveillance data confirms these high prevalence rates. The prevalence of diabetes among Pacific Islanders living in the U.S. is 20.6%.

### DIABETES IN USAPI

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Year</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guam</td>
<td>2002-2003</td>
<td>11%</td>
</tr>
<tr>
<td>FSM</td>
<td>2002</td>
<td>24%</td>
</tr>
<tr>
<td>RMI</td>
<td>2002</td>
<td>30%</td>
</tr>
<tr>
<td>Palau</td>
<td>2006</td>
<td>39%</td>
</tr>
<tr>
<td>American Samoa</td>
<td>2004</td>
<td>47%</td>
</tr>
<tr>
<td>United States</td>
<td>2007</td>
<td>8%</td>
</tr>
</tbody>
</table>

Community members, health practitioners, and systems of care all need to work together to improve diabetes management and prevention in the Pacific Islands. For example, Micronesians trust faith-based leaders the most for information about diabetes. An intervention with faith-based leaders, health care providers, and community members in Chuuk and Hawaii identified and incorporated cultural and spiritual constructs in addressing diabetes medication adherence, nutrition, and physical activity. Among the findings were the barriers to improved nutrition (lack of access affordable healthier alternatives such as non-canned food, overcoming the stigma of fruit and vegetables contaminated by radiation from U.S. bombings of the islands during World War II, cultural and emotional connections to certain food). Some “sedentary” behaviors were associated with “purposeful sitting” and “resting”, which had positive cultural meanings. Much physical activity was defined by cultural age and gender roles. Since Western medicine is viewed as only treating the body, Pacific Islanders also use traditional and local healing methods to treat the spirit and the mind in addition to the body. Having a relationship of trustworthiness with healers and health practitioners is essential. According, a framework based on stewardship, that addresses the spirit, mind, and body, was developed to address the needs of Pacific Islanders with diabetes.

<table>
<thead>
<tr>
<th>Site</th>
<th>Data Source (Year)</th>
<th>Age</th>
<th>% O/O</th>
<th>% Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Am. Samoa</td>
<td>NCD STEPS (2004)</td>
<td>25-64</td>
<td>93.5</td>
<td>47.3</td>
</tr>
<tr>
<td>CNMI</td>
<td>BRFSS (2009)</td>
<td>18+ Years</td>
<td>—</td>
<td>9.8</td>
</tr>
<tr>
<td></td>
<td>Pacific Wellness (2009)</td>
<td>18+ Years</td>
<td>86.8</td>
<td>—</td>
</tr>
<tr>
<td>FSM PNI</td>
<td>NCD STEPS (2002)</td>
<td>25-64 Year</td>
<td>73.1</td>
<td>32.1</td>
</tr>
<tr>
<td>Guam</td>
<td>BRFSS (2009)</td>
<td>18+ Years</td>
<td>—</td>
<td>9.1</td>
</tr>
<tr>
<td>RMI</td>
<td>NCD STEPS (2002)</td>
<td>15-64 Years</td>
<td>62.5</td>
<td>19.6</td>
</tr>
<tr>
<td>Palau</td>
<td>Community Assessment(2003)</td>
<td>15+ Years</td>
<td>—</td>
<td>22.4</td>
</tr>
<tr>
<td></td>
<td>Mini STEPS (2009)</td>
<td>18+ Years</td>
<td>90.0</td>
<td>12.6</td>
</tr>
</tbody>
</table>
Another diabetes management intervention using the Pacific stewardship framework, *Manu o Ku*, has been developed for paraprofessional life coaches at a community health center in Hawaii. The life coaches are trained in counseling, goal setting, and goal tracking improved nutrition, physical activity, and medication adherence for community members with diabetes.

Community-based interventions also can help overcome “clinical inertia” among health care providers who are not meeting recommending guidelines for disease management and outcomes among their patients with diabetes. An internet-based Continuing Medical Education (CME) pilot project is being developed to bring updated knowledge and best practices about diabetes management to health care practitioners in the Pacific Islands who cannot travel to attend CME sessions. The pilot is testing the quality and acceptability of various technologies (live webinars, live-streaming, recorded for downloading/viewing, by groups or tailored for individuals).

Finally, it is important to contextualize the larger public health and health care systems that need to be in place to effectively address chronic diseases. A recent assessment of the capacity of health systems in the Pacific to address chronic diseases shows significant gaps in administrative, clinical, and support systems infrastructure. Improving these systemic and infrastructure capacities is essential to reducing health disparities.
When systems improvements are made, there have been improvements in health outcomes. Beginning in 2005, the Kwajalein Community Health Center in the Republic of the Marshall Islands participated in a Health Resources and Services Administration collaborative to implement the Chronic Care Model for diabetes control. By 2010, the center had seen improvements in clinic attendance, glycemic control, foot screening rate, eye screening rate, coverage rate for cardiac risk reduction medications, dental evaluations, and even flu vaccine coverage among its patients with diabetes. However, the clinical team realizes that sustaining these improvements require more intensive community-based interventions that address policy, system, and environmental barriers (such as access to affordable fresh fruits and vegetables, more walkable pathways on the islands, etc.)

Communities in the Pacific are actively responding to diabetes. We need to understand the context of the Pacific, listen to the voices of Pacific Islanders, and establish and sustain partnerships that have technical support and continuity.

References


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**Closing Remarks**

**Edward A. Chow, MD**

Co-Chair, Asian American Native Hawaiian Pacific Islander Diabetes Coalition

At this conference, we have learned about the different impact of diabetes among Hmong, Filipinos, South Asians, Pacific Islanders. The themes of this conference have been the need for improved prevention, treatment, and research about Asian Americans, Native Hawaiians, and Pacific Islander and diabetes. We need to be person- and community-centered in our approaches. We were reminded to pay attention to the social determinants of health in our communities.

We also learned about methods to improve our communications with those we are trying to reach, whether through traditional communications or with new media and social media to reach the millennials. Together, we are the advocates for Asian Americans, Native Hawaiians, and Pacific Islander on diabetes issues.

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**ASIAN AMERICAN NATIVE HAWAIIAN & PACIFIC ISLANDER DIABETES COALITION**

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Chinese Community Health Care Association