

# Community based participatory approaches to address health disparities in Hawai'i: recent applications in cancer prevention, detection and treatment programs

**Abstract:** Assessment of recent trends in the prevalence and incidence of cancer, and its associated risk and protective factors in the State of Hawai'i illustrate that there are definite ethnic, socio-economic, and geographic health disparities. Disparities in access to health care are reflected in decreased and under utilization of all types of preventive cancer screening tests and decreased proportions of people with health insurance coverage. Increases in obesity mirror U.S. national trends and disproportionately affect certain ethnic groups and those with low income. Tobacco use has increased among at-risk populations including: certain ethnic groups, those with low-income and/or low education and those in rural areas. Data that reveal continuing or worsening health disparities imply that either the old methods have not been effective and/or resources are not available or are not being applied to address such disparities. Promising methodologies and programmatic focuses to reduce health disparities are needed as mechanisms for improving the circumstances of at-risk populations. Community based participatory approaches are described here for cancer prevention, detection, and treatment programs that utilize culturally appropriate methods. **Key Words:** health promotion, health services, preventive health, community participation.

Ann M. Pobutsky<sup>A1</sup>  
 Paran Pordell<sup>A2</sup>  
 Barbara Yamashita<sup>A3</sup>  
 Danette Wong Tomiyasu<sup>A4</sup>  
 Wendy Ku'uipo Nihoa<sup>A5</sup>  
 Kent Kitagawa<sup>A6</sup>  
 Judy Mikami<sup>A7</sup>  
 Tonya Lowery St. John<sup>A8</sup>  
 Jodi Haunani Leslie<sup>A9</sup>

## Introduction

The link between low socio-economic status and poor physical health is one of the oldest known and documented relationships in epidemiology<sup>1-3</sup>. This paper summarizes

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*All authors are with the Hawai'i State Department of Health. A1:Chronic Disease Epidemiologist, Community Health Division. A2:Public Health Prevention Specialist, Centers for Disease Control and Prevention, Epidemiology Program Office, Division of Applied Public Health Training, Public Health Prevention Service. A3:Division Chief, Community Health Division. A4:Branch Chief, Chronic Disease Management and Control Branch. A5:Coordinator, Comprehensive Cancer Control Program. A6:Public Health Administrative Officer, Breast and Cervical Cancer Control Program. A7: Director of Development, Na Pu'uwai, Native Hawaiian Health Care System. A8:Chronic Disease Epidemiologist, Tobacco Prevention and Control Program. A9:Registered Dietician, Physical Activity and Nutrition Section. Contact: Ann M. Pobutsky, Community Health Division, Hawai'i State Department of Health, 1250 Punchbowl St., Rm. 227, Honolulu, HI 96813. Tel: (808) 586-4485. Fax: (808) 586-4791. Email: agpobuts@mail.health.state.hi.us or pobutsky@hawaii.edu.*

the most recent reliable data about cancer, cancer risk and protective factors, and their disproportionate effect on Hawai'i's at-risk sub-populations, which suggests there is a need for adopting new methodologies to address health disparities. These include community-based participatory approaches to affect programmatic change that can lead to efforts to improve community resources and the circumstances of at-risk populations.

The Hawai'i Department of Health has only recently acquired the epidemiological and programmatic capacity to assess the chronic disease burden in the State. At the same time, there are well documented existing health disparities in Hawai'i, particularly among Native Hawaiians and other Pacific Islanders when compared to other ethnic groups<sup>4,5</sup>. These include disparities in access to health care, utilization of services, and poorer health status and health outcomes. Higher rates of morbidity, disability and mortality are found among all disenfranchised and disadvantaged (e.g. low socio-economic status, rural areas) groups in Hawai'i<sup>6</sup>. However, there has been little or no research locally and nationally about the health status of other ethnic groups such as Filipinos in Hawai'i<sup>7</sup>. In addition, geographic and socio-economic factors associated with health disparities have not been explored in depth.

Data that reveal continuing or worsening health disparities imply that either the old methods and interventions have not been fully effective and/or resources may not be available to address such issues. It is the contention of these authors that changing the methodologies used in prevention and other health programs that target Hawai'i's at-risk populations may be one way to assess and address health disparities. This article first describes health disparities relevant to cancer risk and protective factors, and then the conceptual model of community engagement guiding chronic disease programs at the Hawai'i Department of Health. Finally, examples from Hawai'i's cancer programs that

follow community-based participatory approaches to address health disparities are described.

## Data sources

Cancer data comes primarily from the Hawai'i Tumor Registry of the Cancer Research Center of Hawai'i (CRCH)<sup>8</sup>, while data about cancer-related risk and protective factors come from the Hawai'i Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS is an annual land-based telephone survey of non-institutionalized adults ( $\geq 18$  years) that assesses risk factors for disease(s) and conditions related to the ten leading causes of death in the U.S. population, and is conducted in all 50 U.S. states as well as all U.S. territories<sup>9</sup>. The BRFSS data summarized here are derived from the years 1998 through 2002, except where noted. The most recent report, as well as other information about the Hawaii BRFSS, can be accessed online<sup>10</sup>. Surveillance data are not only used to track progress toward reducing disease prevalence, but are an informative resource to provide communities with information so that they can determine ways to decrease risk behaviors and increase protective behaviors through systems and policy changes.

## Cancer incidence and prevalence

Cancer is the second leading cause of death in Hawai'i and accounts for roughly one of every five deaths in the state each year. Like other chronic diseases, Hawai'i generally has lower cancer rates than the continental U.S. For example, the age-adjusted incidence rate for all cancers in the U.S. was 546.9 per 100,000 in 2000; whereas, in Hawai'i during that same year, the age-adjusted incidence rate was 485 per 100,000. However, differences are apparent within Hawai'i's diverse population. Native Hawaiian men have the highest age-adjusted incidence and mortality rates for lung and bronchus cancer and Native Hawaiian women have the highest incidence and mortality rates for breast cancer. Throughout the United States, among "Asian American and Pacific Islander"<sup>11</sup> women, cancer has been the leading cause of death since 1980<sup>12</sup>. With regard to all cancers, there has been a steady increase in overall incidence as well as age-adjusted rates since 1975.

Data from the BRFSS on preventive cancer screenings show that from 1998 to 2002, the proportion of low-income women, as well as women with less education who have ever had a Pap test, decreased. Further, there were overall declines in the proportions of all segments of the population receiving recommended cancer screening tests, including Pap tests, mammograms, sigmoidoscopies and fecal

occult blood tests. At-risk ethnic populations, specifically Filipinos and Native Hawaiians, were the least likely to receive these cancer screenings. However, from 1994 to 2000, there has been a very small but steady increase in Pap screening rates among Filipino and "Other" ethnic groups. This may be attributable to increased efforts to encourage screenings for early detection.

Modifiable behavioral risk factors for chronic diseases such as cancer include tobacco use, poor diet and physical inactivity<sup>13</sup>. Factors protective against some cancers include: not using tobacco, regular physical activity, daily consumption of fruits and vegetables, cancer screening for early detection, as well as access to medical care and having health insurance.

## Tobacco use

In 2002, about one-fifth of the adult population in Hawai'i reported being current smokers, and the proportion of

smokers was higher among men than women. Native Hawaiians had the highest rate of any ethnic group followed by Caucasian, Filipinos, "Others" and Japanese. There were higher proportions of smokers among young people (aged 18-24), those with less income and/or education, the unemployed, as well as those in rural areas of the state (i.e. Kaua'i and Maui counties). It should be noted that "efforts to reduce smoking among the most deprived members of society are unlikely to succeed unless they are supported by measures designed to improve the material circumstances of these individuals<sup>14</sup>." This contention is bolstered by the fact that in Hawai'i in 2002, almost one-half (48.6%) of unemployed people reported smoking, and smoking prevalence has been consistently the highest in this group since 1996.

## Overweight/obesity, physical activity and nutrition

Data from the BRFSS in 2002 illustrate that one-half of the adult population in Hawai'i is overweight or obese. Trend data over the past several years show that Filipinos seem to have the fastest growing rates of obesity compared to other ethnic groups in Hawai'i. Native Hawaiians are more likely to report being obese, as are those of the "Other" ethnicities group and those with low incomes. It should be noted that the BRFSS is based on self-reports, which has been shown to underestimate the prevalence of overweight and obesity in the U.S.<sup>15</sup>. People who are overweight or obese are at risk for numerous health conditions including some specific cancers. Certain ethnic groups are particularly at risk for overweight/obesity, and obesity is also associated with poverty. In Hawai'i, it has been estimated that 25% of all

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cancer deaths among men and 20% of all cancer deaths among women were due to obesity<sup>16</sup>.

Key behavioral risk factors for obesity are sedentary behavior and the lack of physical exercise. The Hawai'i BRFSS has a number of ways to measure estimated physical activity levels based upon self-reports. In 2002, Filipinos reported the lowest amount of leisure time physical activity, followed by Native Hawaiians, "Other" ethnic groups, Japanese and Caucasian. However, over one-half of employed Filipinos reported that they have jobs that require mostly walking or heavy labor, followed by almost one-half of Native Hawaiians. Within all ethnic groups, more than two-thirds reported doing physical activity to lose or maintain their weight. Additionally, the vast majority of Hawai'i's adult population is not getting the recommended minimum of five daily servings of fruits or vegetables.

## Access to health care

Disparities in access to health care have increased since 1998, with the state's most at-risk ethnic group (Native Hawaiians), those in more rural areas of the state (i.e. Kaua'i and Maui counties), and those with less income and less education all increasingly less likely to have health insurance. Men were slightly less likely than women to report having a specific source of on-going health care in 2002. Access to care is one area amenable to change at the organizational, program and policy levels.

## Discussion

Examination of epidemiological data on the cancer burden in Hawai'i clearly demonstrates consistent health disparities, particularly for Native Hawaiians, Filipinos, those with low incomes and/or low education, and those living in rural areas (e.g. neighbor islands). It is also important to note that these diverse groups overlap on many characteristics (e.g. Native Hawaiians who live in rural areas or low-income Filipinos). Similarly, risk behaviors, obesity, access to health care, and preventive practices differ across all subpopulations.

Surveillance of cancer and its risk and protective factors is only the beginning of an assessment process leading to programmatic focal points for change. As noted earlier, data can be used as a tool to illustrate trends, and to engage communities for change<sup>17</sup>. The Community Health Division (Department of Health) regularly disseminates and uses the BRFSS and other data to provide information to community-based organizations and coalitions working on health initiatives. Twenty-five organizations statewide were awarded planning and implementation grants from the Department of Health to develop community-based interventions to promote healthy lifestyles. One project developed on the island of Moloka'i was initiated through a "grass-roots" effort and not from the "top down" as is so common in

funding availability for rural communities. Trend data were examined and the community was surveyed about their community health priorities, which included tobacco use, heart disease/stroke and overweight/obesity. A Moloka'i coalition was formed and included representatives from each area of the island; consumer groups; related agencies and organizations; and businesses, including grocery stores; those that served senior groups; the local Native Hawaiian Health System and a fitness center. The lead agency, *Lamalama Ka Ili*, possessed the cultural sensitivity to ensure that the coalition, projects, community meetings, and any evaluation tool utilized would be the result of consensus among the staff, coalition members, partners, and the community in general. Interventions and policies that resulted included an increase in the number of: 1) businesses with clean indoor air policies, 2) restaurants featuring healthy alternatives on their menus, and 3) places where people could be physically active for free or at affordable rates.

The Centers for Disease Control and Prevention (CDC) is cognizant of this community-based approach: "Simply counting deaths, cases of disease, and other events will not give a complete picture of health disparities. To fully understand how stress, racism, and health are related, researchers must talk with people in the community to get their personal stories and opinions. This type of research goes beyond traditional quantitative studies<sup>18</sup>." Further, for colonized indigenous peoples throughout the Pacific, any research and evaluation being conducted should use an indigenous people's-centered model<sup>19</sup>. Such culturally appropriate methodologies need to be employed (and evaluated) to better engage communities to develop their capacity to address community problems and find resources to deal with them, and, at the same time, have programmatic capacity to facilitate mechanisms to improve circumstances of at risk populations.

## Community engagement and community-based participatory models for change

"In practice, community engagement is a blend of science and art. The science comes from sociology, political science, cultural anthropology, organizational development, psychology, social work and other disciplines with organizing concepts drawn from the literature on community participation, community mobilization, constituency building, community psychology, cultural influences and other sources."

*CDC/ATSDR Committee on Community Engagement, 1997*

Community engagement is defined as the process of working collaboratively with groups who are affiliated by geographic proximity, special interests, or similar situa-

tions with respect to issues affecting their well-being<sup>20</sup>. Community engagement is based upon the assumption that communities are already organized; engagement means mobilizing existing organizational and other networks in order to accomplish new purposes.

While the use of community-based participatory approaches is not new in the social sciences<sup>21</sup> such approaches have shown increasing utility for public health interventions<sup>22</sup>. The aim of such innovative community-based and culturally appropriate approaches is to prevent chronic diseases and premature death among Hawai'i's diverse populations. Two such community-based participatory approaches are described here.

### **Community-based participatory approaches for cancer prevention, detection and treatment**

While there is an abundance of information about diseases and their risk factors among various ethnic groups in Hawai'i, not enough is known about the cultural and other barriers to accessing health care, or changing 'risky' behaviors such as smoking or being sedentary. One study in the U.S. points out that some of the barriers encountered with respect to cervical and breast cancer screening among "Asian American and Pacific Islander" women included discomfort with seeing a male health care provider, fear of being diagnosed with cancer, concerns with transportation and child care, and lack of adequate health insurance to cover the cost of exams or tests<sup>23</sup>. Lack of knowledge about and lack of respect for cultural values and attitudes of diverse groups are barriers to effective communication between patients and their providers, and the paucity of culturally appropriate services available to women is another barrier to effective and timely cancer screening within Native Hawaiian and Filipino communities. A study on Guam that examined ethnicity, socioeconomic status, and the use of mammography, found that ethnicity exerted a strong effect on health care behaviors, even when controlling for additional variables. The authors suggested that there may be psychological or cultural barriers to mammography use among Filipinas and other "Asian and Pacific Islander" women on Guam (compared to Chamorros and Caucasians)<sup>24</sup>.

The Hawai'i Department of Health's cancer programs have developed innovative approaches to engage community stakeholders as well as community participation to prevent, screen and treat cancer among high-risk groups. Hawai'i has two CDC-funded cancer programs within the Department of Health's Chronic Disease Management and

Control Branch of the Community Health Division. The Hawai'i Breast and Cervical Cancer Control Program (BCCCP) is a direct service, health care delivery program that focuses on increasing breast and cervical cancer screening among low-income women that meet the eligibility criteria. The Hawai'i Comprehensive Cancer Control Program (HCCCP) represents an "...integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation," which are the essential components to the creation of an effective statewide cancer control plan<sup>25</sup>.

The formal lead agencies moving the HCCCP planning process forward are the Department of Health, the Cancer Research Center of Hawai'i of the University of Hawai'i at Mānoa, and the American Cancer Society. These organizations consistently work collaboratively and as an integrated team with all cancer stakeholders including health care providers, community-based organizations, health insurers, survivors, and legislators. From its inception in September 2002, the HCCCP has stressed the importance of community engagement and participation, which is clearly reflected in the diverse composition of its community-based coalitions and partnerships. Some of these community partners include Papa Ola Lōkahi, the Hawai'i Medical Services Association (the Hawai'i Blue Cross/Blue Shield franchise), AlohaCare, the Executive Office on Aging, the United Filipino Council of Hawai'i, the Coalition for a Tobacco-Free Hawai'i, the Hawai'i State Legislature, and Hospice Hawai'i. Cancer stakeholders have been tasked over the past two years to identify gaps in cancer services and methods to improve cancer care and reduce the burden of cancer on Hawai'i's residents.

The Community Health Division has always sought out diverse individuals from different ethnic and socio-economic backgrounds and from a multitude of organizations to serve on health promotion and disease prevention and management coalitions<sup>26</sup>. Building the necessary foundation for comprehensive cancer control was no exception. The very first series of Cancer Leadership Institutes as well as former Hawai'i Governor Benjamin Cayetano's Blue Ribbon Cancer Advisory Panel included the participation of lawyers, physicians, nurses, public health professionals, students, legislators, representatives from grass-roots organizations and cancer survivors who represented the interests of the major ethnic groups that comprise Hawai'i's unique diversity. Blue Ribbon Panel members and Leadership Institute attendees were able to share the knowledge and experiences they acquired from working with multi-ethnic communities on each of the islands as well as touch on the experiences they gained from work they have done

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Continuation of diverse participation has been a conscious and deliberate priority. This priority has continued throughout the planning process of the HCCCP and allows the work groups to accomplish their goals and objectives utilizing the most effective, culturally appropriate, and sensitive approaches to competently and realistically address the needs within their respective ethnic populations.

As an illustration, it is extremely beneficial for the HCCCP Coalition to have input and feedback from Filipino health professionals who serve on various work groups including early detection, diagnosis and treatment, and data and surveillance. The individuals who make up the Coalition represent organizations such as the United Filipino Council of Hawaii, the Cancer Information Service-Asian American Network for Cancer Awareness, the Hawai'i Department of Health, the American Cancer Society, Kapi'olani Breast Center, the Kapi'olani Women's and Children's Medical Center, as well as Tripler Army Medical Center. Work group members have many years of experience working within Filipino communities all across Hawai'i, which has allowed them to make valuable connections and continued relationships with these communities. These efforts include culturally astute outreach strategies such as *talking story* (sharing stories), speaking a specific dialect such as Ilocano or Tagalog, or participating in direct service activities within hard-to-reach areas.

Active community engagement as well as the utilization of innovative, culturally sensitive strategies to ensure that women are screened for breast and cervical cancer also represent common practices within the Hawai'i Breast and Cervical Cancer Control Program (BCCCP), which began in 1996. Some of the methodologies used by the Hawai'i BCCCP providers for outreach exemplifies the community engagement process. This was highlighted in a recent study that focused on culturally tailored breast and cervical cancer screenings in diverse communities of "Asian American and Pacific Islander" women at six sites around the U.S., three of which were conducted in Hawai'i targeting Native Hawaiian, Samoan and Filipina women. The researchers found that throughout all six sites, no one model could address the different needs and resources of the different communities<sup>27</sup>. While the researchers found that programs and services needed to be tailored to local communities, they did find that developing trust and interpersonal relationships between providers and community members was a key element to increase cancer screening in all these communities.

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As an illustration, Kalihi-Pālama Health Center and two other BCCCP providers, St. Francis Medical Center and Kapi'olani Women's and Children's Medical Center share a special relationship in that all three work together to increase screening rates among underserved Filipinas. Kalihi-Pālama Health Center is part of a nationwide program entitled CARE (A Community Approach to Responding Early to breast and cervical cancer) that was established to specifically address cultural barriers faced by Asian American and Pacific Islander women receiving breast and cervical cancer screening. As part of the CARE implementation efforts, the center partnered with BCCCP providers, St. Francis Medical Center, and Kapi'olani Women's and Children's Medical Center to provide mammograms and Pap tests to eligible women aged 50-64. The two service providers mentioned above also provided complimentary transportation to and from Kalihi-Pālama Health Center so that

absence of such was no longer a barrier. In addition to providing transportation to and from the screening site, BCCCP, the two hospitals, and Kalihi-Pālama Health Center engaged in a collaborative relationship where Kalihi-Pālama Health Center recruited hard-to-reach

elderly Filipinas by conducting women's health education groups as informal social gatherings. The women were (and still are) provided free screening, basic health education, and a light meal (with music and videos) in order for them to feel more comfortable with breast and/or cervical cancer screening procedures. Kalihi-Pālama Health Center utilized an innovative health education and outreach approach through the use of culturally tailored women's health parties and health education materials. The Filipinas were screened in groups in order to make the experience more comfortable, and to make the process a way to celebrate life, strengthen friendships and expand social support systems, rather than just a visit to the physician's office. Their partners, St. Francis Medical Center, and Kapi'olani Women's Center, provided the direct care services. Kōkua Kalihi Valley Comprehensive Family Services and Wai'anae Coast Comprehensive Health Center are two other BCCCP providers that participated in the CARE program to improve breast and cervical cancer screening rates among Samoan women. BCCCP's partnership with Papa Ola Lōkahi, the advocacy agency for the Native Hawaiian Health Care Systems, has allowed these provider sites to collaborate on the creation of culturally appropriate health education and outreach materials in order to increase breast and cervical cancer screenings among Native Hawaiian women (BCCCP and 'Imi Hale Training and Outreach Networking Conference, 2003). Papa Ola Lōkahi's network of health centers has been instrumental in reaching communities in various and sometimes remote areas of the state.

However, the successes in the recruitment of underserved women underscored a glaring lack of resources for treatment for those women who were diagnosed with cancer through the BCCCP. Almost all received the treatment and care they required through the generosity of community physicians and agencies that provided pro bono services or through an emergency Medicaid waiver. Two women had to return home to their native countries to seek medical care, and one relocated to another state that provided state-funded insurance. As the cost of medical services rose astronomically, the burden on community resources became unbearable to the point where physicians and specialists like anesthesiologists were unwilling to take on more cases without reimbursement.

The passage of the Breast and Cervical Cancer and Prevention and Treatment Act of 2000 (BCCPTA) made Federal funding available for the treatment of women diagnosed with cancer through the BCCCP<sup>28</sup>. With the State's passage and implementation of a corollary bill providing state funding for women who do not qualify for federal aid, treatment issues are addressed for the varied groups of ethnically diverse women that are served through the program. This enables the BCCCP to provide the full spectrum of services, from screening to treatment, to women who otherwise would have no access to these lifesaving procedures because of socio-economic disparities.

Health education and outreach measures are also currently being implemented in Hawai'i through various collaborations and partnerships with the Cancer Information Service, Hawai'i Tumor Registry, American Cancer Society, 'Imi Hale, the Hawai'i Department of Health, and the University of Hawai'i, with the active participation of community members. Involving community leaders in designing health interventions to address these barriers allows cultural beliefs and values to be embedded within the health education messages, which will hopefully improve health outcomes in Filipina and Native Hawaiian women across the state.

## Discussion

It is important to note that using innovative methodologies for engaging communities in the change process to address health disparities does not mean that communities must solve their own problems all by themselves. There is the "...possibility that focusing on what materially and politically disenfranchised communities can do for themselves may be akin to victim blaming at the community level that reinforces low expectations for structural change<sup>29</sup>." Instead, communities are active participants at all levels in

the change process (including structural change), and are not just viewed as passive entities or "target" groups or particular communities for which health promotion or social marketing campaigns are aimed. Public health agencies can help facilitate this process of community engagement for change through organizational, programmatic and policy changes, as exemplified here for cancer.

Even so, returning to the issue of income inequality and other material and social conditions that are associated with population health, the health of particular groups always resurfaces, particularly in relation to groups who are socio-economically disadvantaged. Health disparities or inequities are the result of "...differential accumulation of exposures and experiences that have their sources in the material world<sup>30</sup>." Taking such considerations into account, engaging diverse communities for change necessitates being able to adapt strategies to varied cultural norms, beliefs and views about health because of their diverse histories and experiences.

Income and other socio-economic disparities are correlated with health disparities; as income gaps widen, so do gaps in health, as well as access to health care<sup>31</sup>. The CDC

points out that poverty is not the only factor leading to health disparities: "...covert racism and discrimination, chronic stress, residential, economic or racial segregation and the lack of occupational and/or educational opportunities, are some of the main factors that lead to health disparities between racial or ethnic groups<sup>32</sup>." Currently, there is a lack of information about Hawai'i's diverse ethnic groups' perceptions or experiences of racism and discrimination and the impacts on their health and on health disparities. However, there is a clear need to determine why health disparities continue and why such disparities have become more pronounced among particular segments of Hawai'i's population<sup>33</sup>. Further, it is important to note that particular groups should not be singled out as "the problem" (e.g. those with low income); rather, the circumstances of such groups are "the problem" and circumstances are amenable to change.

We also know that throughout the U.S. there has been an increasing gap between the rich and the poor over the past two decades<sup>34</sup>, and this has fueled the renewed interest in the socioeconomic determinants of health<sup>35</sup>. However, there have been decreases in resources provided to public infrastructure such as health and education, while at the same time there are increased demands on public health. This poses a challenge for public health programs to address disparities by ensuring equitable distribution of resources through programs, and finding ways to improve the circumstances of individuals and communities for im-

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proved health. Additionally, several studies have illustrated that socio-economic, ethnic or even gender differences in health outcomes are not easily explained by the higher prevalence of health risk behaviors in low income groups, or ethnic minorities<sup>36,37</sup>. More research about the mechanisms of how inequities impact health is needed.

Along with more research and evaluation being done about cultural competence<sup>38</sup>, community-based participatory approaches also lead to more information from the community about the 'why' behind health outcomes. Inclusion is critical, as is the socio-cultural component which fully acknowledges the norms and values of diverse communities. For disenfranchised groups such as indigenous Pacific Islanders, the community-based participatory model makes sense, whereby the approach is 'of and by' communities (ethnic or geographic) rather than 'for and to' them.

## Conclusion

Public health departments which use community-based participatory approaches can play a critical role in bringing community networks and organizations together to link communities in need of services. Such approaches may lead to reduced health disparities by engaging communities at all stages of the public health planning, implementation and service delivery process to effect change.

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