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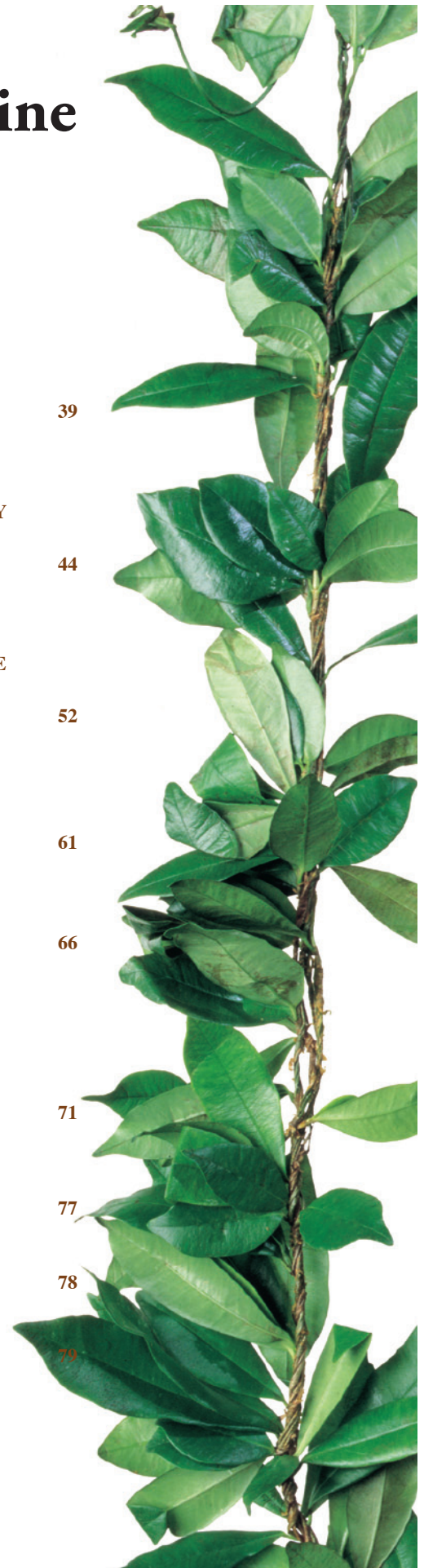
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# Hawai'i Journal of Medicine & Public Health

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# An Uncommon Pairing of common Tumors: Case Report of Ductal Carcinoma *in situ* Within Fibroadenoma

Ashley Marumoto MD; Susan Steinemann MD; Nancy Furumoto MD; and Stacey Woodruff MD

## Abstract

*Fibroadenomas are common benign tumors of the female breast. In the appropriate clinical setting, they are often managed expectantly without excision. Rarely, cancer may arise within a fibroadenoma, and this diagnosis mandates prompt treatment for malignancy. We present the case of a 70-year-old Samoan woman with ductal carcinoma in situ (DCIS) arising within a fibroadenoma. Health care practitioners should be aware of the possibility, particularly in older women, of finding carcinoma within a fibroadenoma, which informs the rationale for prompt surgical evaluation and follow up of all breast masses.*

## Keywords

Breast cancer, Ductal carcinoma in situ, Fibroadenoma

## Abbreviations

ACOSOG: American College of Surgeons Oncology Group

ACRIN: American College of Radiology Imaging Network

ATAC: Anastrozole Tamoxifen Alone and in Combination

BIG: Breast International Group

CALGB: Cancer and Leukemia Group B

CT: Computed tomography

DCE-bMRI: Dynamic Contrast-enhanced Breast Magnetic Resonance Imaging

DCIS: Ductal carcinoma in situ

ECOG: Eastern Cooperative Oncology Group

ER: Estrogen receptor

Her-2: Human Epidermal Growth Factor Receptor 2

NCCN: National Comprehensive Cancer Network

PR: Progesterone receptor

## Introduction

Hawai'i has a growing elderly population. According to the 2016 United States Census Bureau, 17% of Hawaii's population is over the age of 65, up from 14% in 2010.<sup>1</sup> Breast cancer is the most common cancer among women in Hawai'i, accounting for 33% of cancers, and the most common cancer found in Samoan women living in Hawai'i.<sup>2</sup> Over 1,000 women are diagnosed with invasive breast cancer in Hawai'i every year, with an additional 300 women diagnosed with in situ disease.<sup>2</sup> As of 2013, Hawai'i ranked number six in the country for incidence of invasive breast cancer, with Native Hawaiians having the highest rates of new diagnoses. For these reasons, vigilance amongst Hawai'i practitioners is especially warranted.

Fibroadenomas are among the most common benign breast tumors. As they are hormone responsive, peak incidence is in the second or third decade of life. Fibroadenomas are composed of stromal and epithelial components and are not considered pre-malignant. They may be classified as simple or complex based on histologic features. Data conflicts as to whether there is an increased risk of breast cancer among women with "complex" fibroadenoma.<sup>3,4</sup> Observation or excisional biopsy are accepted treatment options for fibroadenomas depending on the tumor size and age of the patient. Nevertheless, there have been reports of

cancerous lesions developing within fibroadenomas. Health care practitioners should be aware of the possibility, particularly in older women, of finding carcinoma within fibroadenomas, which informs the rationale for prompt surgical evaluation and follow up of all breast masses. We present the case of a 70-year-old Samoan woman with ductal carcinoma in situ (DCIS) arising within a fibroadenoma.

## Case Report

A 70-year-old Samoan woman underwent a chest X-ray after presenting to the emergency department with shortness of breath. The chest X-ray revealed tracheal deviation and was suspicious for a thyroid mass. Further work up included a chest computed tomography (CT) significant for an incidental right breast mass. Her last screening mammogram four years prior to her presentation had not shown the mass that was seen on the current CT. She was referred to a general surgeon for further evaluation and management of the incidental breast mass.

She was asymptomatic in regards to the breast mass. Her breast history was significant for multiple benign breast cysts. Her menarche was at 13 years of age. She experienced menopause in her 50s, and she had five pregnancies which resulted in three live births, with her first child born when she was age 27. She breastfed all three of her children. She had no prior use of oral contraceptives or hormone replacement therapy. She was a lifetime nonsmoker. There was no known family history of breast cancer or other gynecologic cancers. Her physical exam was significant for a two centimeter palpable, mobile mass in the upper outer right breast at the nine o'clock position, three centimeters from the nipple. There was no axillary or supraclavicular lymphadenopathy. Mammography revealed a 2.8 centimeter mass in the right upper outer quadrant without microcalcifications. The breast tissue was heterogeneously dense.

An ultrasound revealed an irregularly shaped, circumscribed mass at the nine to ten o'clock position measuring 2.4 x 1.6 x 2.2 centimeters without right axillary lymphadenopathy. An ultrasound-guided core biopsy revealed a fibroepithelial lesion; fibroadenoma versus phyllodes tumor. The patient underwent excisional biopsy which revealed a fibroadenoma with a one centimeter area of intermediate-grade ductal carcinoma in situ (DCIS), estrogen receptor (ER) positive, progesterone receptor (PR) negative (Figure 1a-c). All margins were greater than two millimeters. The patient completed right breast radiation therapy and is currently receiving tamoxifen, due to osteoporosis identified on bone density testing. At one-year follow-up, she had no clinical or radiographic evidence of disease.

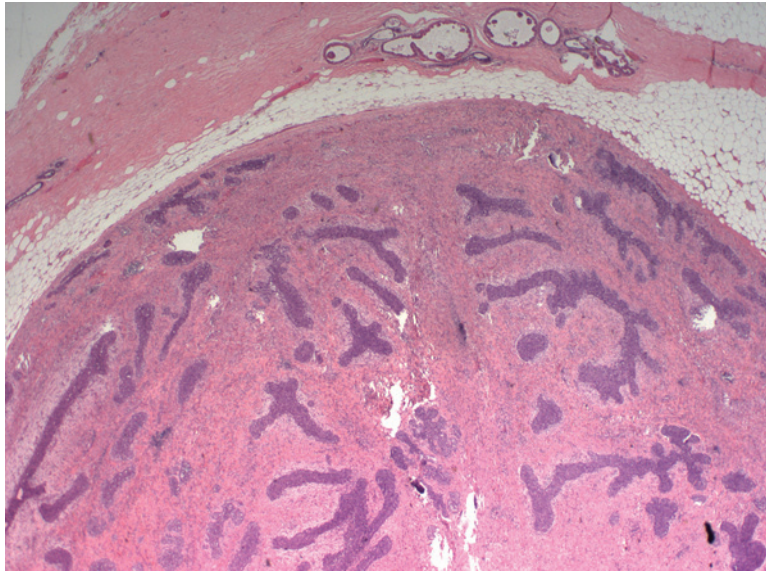


Figure 1a. Low Power Image of Surgical specimen

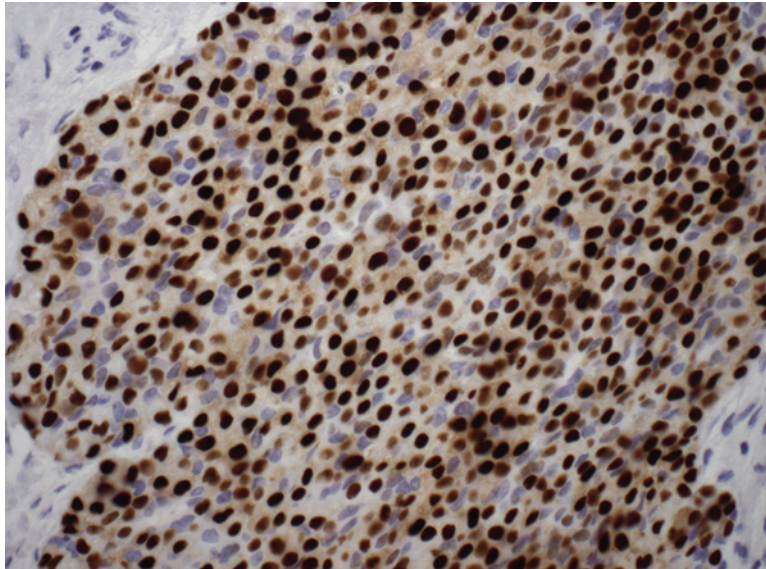


Figure 1b. High Power Image of DCIS with Estrogen Receptor Staining (Positive)

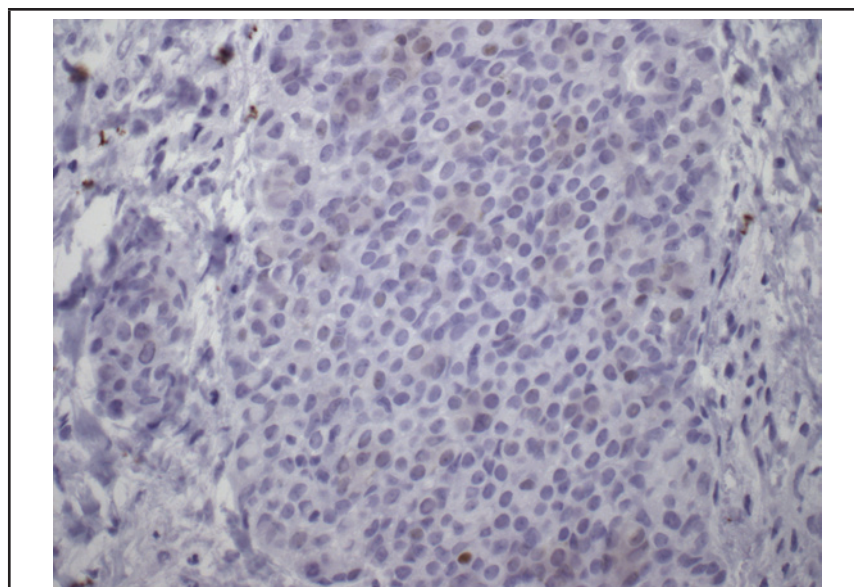


Figure 1c. High Power Image of DCIS with Progesterone Receptor Staining (Negative)

## Discussion

While ductal carcinoma in situ is considered a non-invasive cancer, fibroadenoma is not pre-malignant. Although fibroadenomas are typically benign, other lesions can arise within a fibroadenoma, which was first reported by Cheatle and Cutler in 1931.<sup>5</sup> Carcinoma within a fibroadenoma occurs rarely, with most studies reporting an incidence of less than 1%.<sup>3,6-9</sup> Carcinoma in situ was the predominant type of malignancy arising within fibroadenomas.<sup>6</sup> Cases of breast carcinoma within a fibroadenoma typically occur at an older age than pure fibroadenomas, with mean age at detection between 40 to 52 years old.<sup>6-7,9</sup>

Observation of fibroadenomas is an accepted management practice. However, diagnostic uncertainty or features that confer cancer risk warrant biopsy. It has been debated whether or not complex fibroadenomas, which include those with cysts, sclerosing adenosis, epithelial calcifications, or papillary apocrine metaplasia, increase the risk of malignancy.<sup>3,4</sup> The Mayo Clinic Benign Breast Disease Cohort Study found that a complex fibroadenoma was not an independent risk marker for breast cancer.<sup>4</sup> In 2015, Hubbard, et al, sought to further define criteria for excision of fibroadenomas: age greater than 35 years old, an immobile or poorly-circumscribed mass, a size greater than 2.5 centimeters, or biopsy not definitive for fibroadenoma were risk factors for non-fibroadenoma lesions arising within fibroadenomas.<sup>10</sup> While prospective studies need to be performed for further delineation, our patient's presentation supports these findings.

In contrast to fibroadenomas, phyllodes tumors are extremely rare breast tumors with less than 1% incidence.<sup>11</sup> They may be benign, borderline, or malignant, with benign lesions being more common.<sup>11</sup> They occur in women in the third and fourth decades of life, and similar to fibroadenomas, they present as

a firm, painless, mobile mass and are difficult to discern from fibroadenomas on imaging.<sup>12</sup> The risk of malignancy increases with the size of the tumor.<sup>13</sup> *National Comprehensive Cancer Network (NCCN)* guidelines recommend wide local excision with one centimeter margin without need for axillary staging due to hematogenous, as opposed to lymphatic, spread.<sup>14</sup> Chemotherapy for local disease is not indicated.<sup>14</sup> Radiation may be recommended if a malignant phyllodes tumor is found on final pathology.<sup>15</sup>

Not surprisingly, total DCIS detection rates increase with age.<sup>16</sup> The hallmark mammographic finding of DCIS is microcalcifications, which were notably absent in this patient. A case report by Park et al reporting DCIS within a fibroadenoma also found that mammographic microcalcifications were absent.<sup>17</sup> While it can vary, enhancement of fibroadenomas during dynamic contrast-enhanced breast magnetic resonance imaging (DCE-bMRI) usually persists until the delayed phase, whereas areas of DCIS have a different pattern of contrast enhancement and washout.<sup>17</sup> As technology continues to develop, perhaps DCE-bMRI may become the modality of choice to determine whether presumed benign fibroadenomas have risk factors for intralesional carcinoma.

Multiple studies have proven the benefit of radiation therapy on survival and recurrence when used in conjunction with lumpectomy. This is considered the standard of care for breast conservation therapy for DCIS and breast cancer. However, radiation is not without risk, cost, and impact on quality of life for patients. Specifically, lung cancer and heart disease are known long term potential complications of breast cancer radiation therapy, especially for long-term smokers.<sup>18</sup>

For these reasons, recent studies have attempted to delineate the role of radiotherapy in certain populations, particularly the elderly. Studies have found that patients greater than seventy

years old have local control after radiotherapy, but this does not impact their overall survival. The Cancer and Leukemia Group B (CALGB) 9343 trial sought to address whether there was a subgroup of patients, particularly elderly patients, in whom radiation might not benefit and thus could be deferred.<sup>19</sup> The study randomized women seventy years old and over with ER-positive early stage breast cancer to undergo lumpectomy with five years of tamoxifen with or without breast radiotherapy. The study showed that radiation did not significantly decrease the rate of mastectomy for local recurrence, increase survival rate, or increase rate of freedom from distant metastases.<sup>19</sup> The study's authors recommended tamoxifen alone as a reasonable choice for adjuvant treatment in this cohort of patients.

It is important to note that while these studies are historically relevant, the current standard of care in elderly women with breast cancer is treatment with an aromatase inhibitor. The superiority of aromatase inhibitors was demonstrated in the Anastrozole Tamoxifen Alone and in Combination (ATAC) trial and the Breast International Group (BIG) 1-98 trial.<sup>21,22</sup> However, anastrozole is associated with significant bone mineral density loss and increased bone turnover.<sup>23</sup> As such, for women with osteopenia and osteoporosis, aromatase inhibitors should be used with caution and clinicians should incorporate strategies to prevent further bone loss. These include lifestyle modifications such as weight bearing exercises, avoiding tobacco and alcohol, and adequate calcium and vitamin D intake.<sup>24,25</sup> NCCN guidelines recommend consideration of adjuvant bisphosphonate in post-menopausal women receiving adjuvant endocrine therapy.<sup>26</sup> This recommendation may differ depending on the Human Epidermal Growth Factor Receptor 2 (Her-2) status of the tumor as evidenced by a recent study by Haque et al.<sup>27</sup> Breast cancer specific survival increased when adjuvant radiotherapy was administered to Her-2 negative patients greater than 70 years old, regardless of ER status.<sup>27</sup> As it relates to DCIS, the Eastern Cooperative Oncology Group (ECOG) and the American College of Radiology Imaging Network (ACRIN) E5194 trial, a prospective 5-year study with over 500 patients, demonstrated an increased risk of developing ipsilateral breast event in cases of DCIS with lumpectomy alone.<sup>28</sup> As such, current data conflicts on whether or not it is safe to forego radiation after lumpectomy, particularly in the elderly.

Additional considerations include the influence on the type of radiation on outcomes. As technology continues to develop, different types of radiation are now available. While the radiation included in the American College of Surgeons Oncology Group (ACOSOG) Z011 was tangential, whole breast irradiation, accelerated partial breast irradiation, and hypofractionated whole breast radiation are now available.<sup>29,30</sup> For select women age greater than 50 years old with negative margins by greater than 2 millimeters, these treatments have been found to be shorter, more cost effective alternatives that maintain oncologic outcomes.<sup>31</sup>

Lastly, surgical margins have long been a topic of debate. In 1999, a retrospective study by Silverstein recommended one centimeter margins for DCIS.<sup>32</sup> Concordant with the transition to less invasive approaches, in 2014 the Society of Surgical Oncology and American Society of Radiation Oncology recommended “no ink on tumor” for invasive breast cancer.<sup>33</sup> For DCIS, due to the possibility of skip lesions, along with higher recurrence rates with closer margins, a margin of 2-mm has now been recommended.<sup>34</sup> After the change in margin guidelines, there has been an increase in lumpectomy as the sole surgical procedure with decrease in subsequent surgery post-lumpectomy.<sup>35</sup>

In conclusion, although rare, multiple cases of carcinoma within fibroadenomas have been reported. While the mean age for most are in the fifth decade, this patient presented at the age of 70. As Hawaii's population is comprised of a large number of elderly, clinicians must be vigilant as to the possibility of an alternative diagnosis in elderly patients with fibroadenoma.

In addition to highlighting a rare case of DCIS within a fibroadenoma, this case highlights the evolution of breast cancer surgery, from maximally invasive to more selective, conservative interventions. Research is quickly evolving allowing clinicians the opportunity to make decisions based on a patient's individual circumstances.

### **Conflict of Interest**

None of the authors identify a conflict of interest.

#### **Authors' Affiliations:**

- Department of Surgery, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (AM, SS, NF, SW)
- Department of Surgery, Pali Momi Medical Center, Aiea, HI (SW)

#### **Correspondence to:**

Stacey Woodruff MD; Department of Surgery, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI 96813; Email: slwoodru@hawaii.edu

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# The Association Between Risk Behaviors and Race/ Ethnicity on Dental Visiting Among High School Students in Hawai'i: Hawai'i Youth Risk Behavior Survey, 2013, 2015

Alex Espinoza MPH; Donald K. Hayes MD, MPH; Sarah Uehara MHMS; Deborah Mattheus PhD, MSN, CPNP, APRN-Rx; and Jennifer Domagalski DDS

## Abstract

*Risk behaviors are known to adversely affect health outcomes, but the relationship between youth risk behaviors and oral health remains unclear. The objective of this study is to examine the likelihood of dental visiting among Hawai'i public high school students by demographic factors and number of adverse risk behaviors. Aggregated 2013 and 2015 Hawai'i public high school Youth Risk and Behavior Survey (YRBS) data was analyzed from 10,720 students. Results showed that, overall, 77.1% of students reported a dental visit in the past 12 months. Students who were ages 15, 16, 17, and  $\geq 18$  years old were less likely than students who were  $\leq 14$  years old to visit a dentist. Those who identified as Hispanic, Native Hawaiian, Filipino, Other Pacific Islander, and students who identified as more than one race/ethnicity were less likely to visit the dentist than their white counterparts. In addition, students having either 4 risk behaviors or  $\geq 5$  risk behaviors were less likely to report a dental visit than those with no risk behaviors. These findings support the presence of disparities in oral health care utilization among high school students in Hawai'i and reveal a significant association between age, number of risk behaviors, and race/ethnicity with the likelihood of utilizing dental services. Oral health programs should consider screening for risk factors and multiple risk behaviors, integrating with other health programs that share similar risk behaviors, and account for cultural differences in their development, implementation, and evaluation.*

## Introduction

Disease of the orofacial complex is an important public health issue because of the bidirectional relationship between oral health and overall health. While oral infections and disease can be the source of, or impact systemic health issues, they can also be the resulting manifestations of general health conditions. On a functional level, oral health status not only affects what or how we eat, but also our appearance and ability to communicate, breathe, swallow, work, and learn. Psychologically, disease of the oral cavity can affect levels of stress and depression by decreasing individual self-image, confidence, and social interactions.<sup>1</sup>

Children and adolescents are especially impacted by poor oral health. According to *Oral Health in America: A Report of the Surgeon General*, early childhood caries (ECC) is the most common chronic childhood disease.<sup>1</sup> Dye, et al, report that 21.3% of American children ages 6 to 11 in 2011-2012, had dental caries experience in primary teeth, and that nearly three in five American adolescents ages 12 to 19 had dental caries experience in permanent teeth.<sup>2</sup> The report also states that, despite poor oral health being highly preventable, an estimated 15% of American adolescents had untreated dental caries currently impacting their lives.<sup>2</sup>

Prevention is the key to good oral health status and includes oral hygiene, proper diet, fluoride exposure, and regular dental visits. The American Academy of Pediatric Dentistry (AAPD) states that children should see the dentist within six months of the eruption of their first tooth, before the child is one year old, with intervals between exams most commonly being every six months,<sup>3</sup> and routine preventive dental visits should continue into adolescence.<sup>4</sup> These guidelines allow for the early detection and treatment of disease, and parental education.

Due to the importance of dental visits in oral health, it is imperative to understand what drives the use of dental services by children and adolescents. Berdahl, et al, found that 41.9% of American children ages 0 to 17 in the years 2010 to 2012 reported that they had been to the dentist for general dental care, excluding orthodontic visits.<sup>5</sup> During this time, the annual cost of general dental care for American children equaled \$9.13 billion with out-of-pocket costs covering nearly a quarter of those expenditures.<sup>5</sup> It should be noted that the \$9.13 billion accounted for 8.8% of all annual pediatric health care expenses.<sup>5</sup>

National surveillance studies are vital to improving federal priorities in tackling oral health in children, but regional disparities in disease burden do exist. The 2015 *Hawaii Smiles* report found that Hawaii's children are especially impacted by dental disease, with 71% of third grade children having dental caries experience compared to 52% nationwide.<sup>6</sup> The report also found that many Hawai'i children are at risk of more severe outcomes with 22% of third graders having untreated tooth decay and 7% in pain or suffering from significant infection and in need of urgent dental treatment.<sup>6</sup> Consequently, Hawai'i—the state with the highest childhood caries experience in the country—was ranked as the worst state on several dental report cards published by The Pew Center on the States.<sup>7-9</sup> The objective of this study is to document oral health utilization disparities in the adolescent community of Hawai'i to help inform State efforts to improve oral health across the life span.

## Materials and Methods

The Hawai'i Youth Risk Behavior Survey (YRBS) is administered in public high schools and middle schools throughout the state during odd-numbered years (more information is available at: <http://hhdw.org/health-reports-data/data-source/yrbs-reports/>). Hawai'i YRBS is part of the Youth Risk Behavior Surveillance System (YRBSS) developed by the US



Department of Health and Human Services (HHS), Centers for Disease Control and Prevention (CDC), and state, territorial, tribal, and local governments. YRBS collects data in six categories of health-related risk behaviors including injuries and violence, sexual behaviors, alcohol and drug use, tobacco use, dietary behaviors, and physical activity as well as demographic data including age, sex, and race/ethnicity. Data from 10,720 respondents of the 2013 and 2015 Hawai'i high school YRBS cohorts were analyzed. Information on dentist visits was available for 9,955 students (92.9%) and 890 students (8.3%) responded "Not sure" to having had a dentist visit. The "Not sure" and missing responses were excluded from the analysis leaving a study sample of 9,065 students (84.6%).

The outcome of interest examined in the study was the presence of a dentist visit in the past 12 months, and was defined as a response of "during the past 12 months" to the question: "When was the last time you saw a dentist for a checkup, exam, teeth cleaning, or other dental work?" The responses "Between 12 and 24 months ago," "More than 24 months ago," and "Never" were combined into a single "No" response category.

Self-reported race/ethnicity options in the survey included white, Hispanic or Latino, Native Hawaiian, Filipino, Japanese, Other Pacific Islander, some other race/ethnicity, and those who do not identify as only one race/ethnicity category. The term white used in this report refers to non-Hispanic whites. Age was categorized as 14 years old or younger, 15 years old, 16 years old, 17 years old, and 18 years or older.

The variable "number of risk behaviors" was measured using an index created from several individual questions on adverse risk behaviors in the YRBS survey. These were chosen based on questions over risk behaviors present in the Hawai'i YRBS that have been associated with adverse oral health effects in previous studies.<sup>10-29</sup> Seven different risk behaviors were included in the index: soda consumption, cigarette smoking, alcohol consumption, marijuana use, overweight/obesity, physical activity, and illicit drug use. All risk behaviors responses were dichotomized into "yes" or "no" responses, and skipped questions were categorized as missing. Only students with valid responses for each individual risk behavior used in the index were included in the estimates for number of risk behaviors ( $n=7,491$ ). Students with missing responses in any of the single risk behaviors were excluded from the index variable. Soda consumption was defined as having consumed at least one can, bottle, or glass of soda or pop during the past 7 days. For cigarette use, alcohol consumption, and marijuana use, the risk behavior was considered present if the student used or consumed the substance during the past 30 days. Adherence to physical activity recommendations was defined as having exercised at least 60 minutes per day during the past 7 days. Overweight and obesity were defined as being  $\geq 85$ th and  $\geq 95$ th percentile for body mass index (BMI), respectively, and combined into a single category (ie, overweight or obese status). Individual BMIs were calculated using self-reported height and weight and were based on sex and age-specific reference data from the 2000 CDC growth chart. Finally, illicit drug use was considered pres-

ent if the student had ever used any form of cocaine, inhalant, heroin, or methamphetamines in their lifetime. Individual risk behaviors were then consolidated into an index that measured the presence of 0, 1, 2, 3, 4, and  $\geq 5$  risk behaviors.

All response data were weighted to be reflective of Hawaii's public high school population. Analyses were performed using SAS version 9.4 (SAS Institute Inc, Cary, NC) and SUDAAN version 11.01 (Research Triangle Institute, Research Triangle Park, NC) to account for complex survey design. Initial data analysis generated prevalence estimates and respective 95% confidence intervals (CI) of age, race/ethnicity, sex, and number of risk behaviors as well as bivariate analyses using chi-squared tests against dentist visit in the past 12 months. Log-binomial regression that included age, sex, race/ethnicity, and number of risk behaviors was used to calculate risk ratios (RR) for likelihood of dentist visit in the past 12 months. Risk ratios were used to avoid inflation of association estimates due to the common prevalence of the outcome variable.<sup>30,31</sup> A *P*-value of .05 was considered significant.

## Results

Of the 9,065 students included in this study, more than 80.0% of students were of racial/ethnic groups other than white, with the largest represented group identifying as Filipino (29.0%). Students who identified as Native Hawaiian comprised 11.7% of the study population (Table 1). Overall, 73.2% of students had multiple ( $\geq 2$ ) risk behaviors, and 3.5% had no risk behaviors (Figure 1). The prevalence estimates for the seven individual risk behaviors were 67.0%, soda consumption; 9.5%, cigarette use; 25.2%, alcohol consumption; 18.6%, marijuana use; 27.5%, overweight/obese; 79.4%, non-adherence to physical activity recommendations; and 11.7%, illicit drug use (Figure 2). Among those with one risk behavior, non-adherence to physical activity recommendations was the most common (57.9%, 95% CI 54.0–61.7), followed by soda consumption (34.5%, 95% CI 30.6–38.7) and overweight/obese status (4.2%, 95% CI 3.2–5.4). Among those with two risk behaviors, the most common combinations were soda consumption and non-adherence to physical activity guidelines (66.7%, 95% CI 63.7–69.6), overweight/obese status and non-adherence to physical activity guidelines (13.3%, 95% CI 11.3–15.6), and soda consumption and overweight/obese status (5.1%, 95% CI 4.0–6.6). Among those with three risk behaviors, all of the most common combinations included soda consumption; these estimates were 49.2% (95% CI 45.2–53.1) in combination with non-adherence to physical activity guidelines and overweight/obese status, 14.8% (95% CI 12.3–17.6) in combination with non-adherence to physical activity recommendations and alcohol consumption, and 5.7% (95% CI 4.3–7.7) in combination with non-adherence to physical activity recommendations and marijuana use. Among the most common combinations of four risk behaviors, all combinations included soda consumption and non-adherence to physical activity guidelines; these estimates were 26.5% (95% CI 22.7–30.1) in combination with alcohol consumption and marijuana use, 18.9% (95% CI 15.8–22.5)

in combination with alcohol consumption and overweight/obese status, and 8.2% (95% CI 5.3–12.7) in combination with marijuana use and overweight/obese status.

In the bivariate analysis, males (75.4%) were less likely to visit the dentist compared to females (79.0%) (Table 2). The likelihood of having a dentist visit was highest among Japanese (85.4%) and white (83.3%) students and lowest in Native Hawaiian (71.6%), Hispanic/Latino (66.3%), and Other Pacific Islander (64.0%) students. Furthermore, students were less likely to visit the dentist with increasing number of risk behaviors.

In the adjusted analysis, students who were ages 15 (RR=0.95, 95% CI=0.91–0.99), 16 (RR=0.93, 95% CI=0.88–0.97), 17 (RR=0.92, 95% CI=0.88–0.95), and ≥ 18 years old (RR=0.91, 95% CI=0.86–0.97) were less likely than students who were ≤ 14 years old to visit a dentist. Students who identified as Other Pacific Islander (RR=0.82, 95% CI=0.75–0.89), Native Hawaiian (RR=0.87, 95% CI=0.82–0.92), Hispanic/Latino (RR=0.88, 95% CI=0.79–0.97), Filipino (RR=0.92, 95% CI=0.87–0.97), and those who did not identify as a single race/ethnicity (RR=0.90, 95% CI=0.86–0.95) were less likely than whites to visit the dentist (Table 3). The analysis also found that students with either four [RR = 0.91 (CI: 0.84, 0.99)] or ≥ five [RR = 0.90 (CI: 0.82, 0.99)] risk behaviors were less likely to visit the dentist compared to those with no risk behaviors.

## Discussion

The results of this study confirm the presence of disparate outcomes in oral health care utilization among Hawai'i high school students based on age, race/ethnicity and number of risk behaviors. We found that students who were older than 14 years of age were less likely to visit the dentist compared to students who were 14 years of age or younger. Students who identified as Other Pacific Islander, Native Hawaiian, Hispanic/Latino, Filipino, and those who did not identify as a single race/ethnicity were also more likely than whites to visit the dentist. In addition, students categorized as having either four or ≥ five risk behaviors were associated with lower likelihood of dentist visit compared to those with no risk behaviors and, of the seven oral health risk behaviors examined, 73.2% of students in the study population had multiple (≥2) risk behaviors. Our study measures the association between risk factors and risk behaviors on dental visits among Hawai'i public high school students and orients the findings in the context of the national narrative surrounding oral health in adolescents.

Most research regarding the differential likelihood of dental visit between individual years of age tend to focus on the early years of childhood. The closest comparison that could be made with respect to our results were those of the 2015 *Hawaii Oral Health: Key Findings* report that showed that 78% of middle school students had a dental visit in the past year compared to 77% of high school students in the 2013 YRBS results.<sup>32</sup> Although the results of the *Hawaii Oral Health: Key Findings* report support our own findings that younger students (ie, middle school students) were more likely to have a dental visit than older students (ie, high school students), no direct comparison

Table 1. Selected Characteristics of Public High School Students in Hawai'i, Hawai'i YRBS, 2013, 2015 (N = 9,065).

Characteristic	n <sup>a</sup>	% <sup>b</sup>	95% CI <sup>c</sup>
<b>Sex</b>			
Female	4744	51.5	49.6–53.4
Male	4264	48.5	46.6–50.5
Missing	57		
<b>Age (years)</b>			
≤14	1369	15.5	13.0–18.3
15	2349	25.9	23.2–28.7
16	2278	24.9	22.6–27.4
17	2199	23.0	20.1–25.1
≥18	854	10.8	9.0–13.0
Missing	16		
<b>Race / Ethnicity</b>			
Hispanic or Latino	363	2.2	1.8–2.6
Native Hawaiian	1306	11.7	9.2–14.8
Filipino	2104	29.0	26.8–31.4
Japanese	875	13.7	11.5–16.3
White	1044	15.0	11.4–19.7
Other PI	525	4.2	3.5–5.0
Some other race/ethnicity	495	4.8	3.9–6.1
I do not describe myself as only one race or ethnicity	2217	19.3	18.0–20.7
Missing	136		

<sup>a</sup>Unweighted number of survey respondents. <sup>b</sup>Weighted percentages, except for missing categories. Missing and unknown categories excluded from weighted calculations. <sup>c</sup>Confidence interval around the weighted prevalence estimate.

could be made on individual years of age and the *Oral Health: Key Findings* report lacked statistical testing to discern whether differences were statistically significant. More studies examining the differential likelihood of dental visit between individual years of age are needed to validate the results of our findings. Additionally, future studies using YRBS data should include the results of the middle school YRBS to give a broader age range to analyze when examining questions surrounding dental visiting.

The 2015 *Hawaii Smiles* report on oral health highlights the presence of racial/ethnic disparities among third graders in Hawai'i public schools.<sup>6</sup> Our results show a similar trend among students in Hawai'i public high schools. This study also justifies the use of Asian/Pacific Islander subpopulations in the Hawai'i YRBS, thereby allowing for the identification of health disparities in populations which, as Britton, et al, argue, are often obscured by aggregation in national health surveys.<sup>33</sup> Moreover, Wu, et al, assert that racial/ethnic differences across health outcomes in Hawai'i subpopulations are tied to socioeconomic disparities.<sup>34</sup> For example, 2015 Behavioral Risk Factor Surveillance System (BRFSS) data shows that only 21% of Native Hawaiian/ Pacific Islanders have an annual household

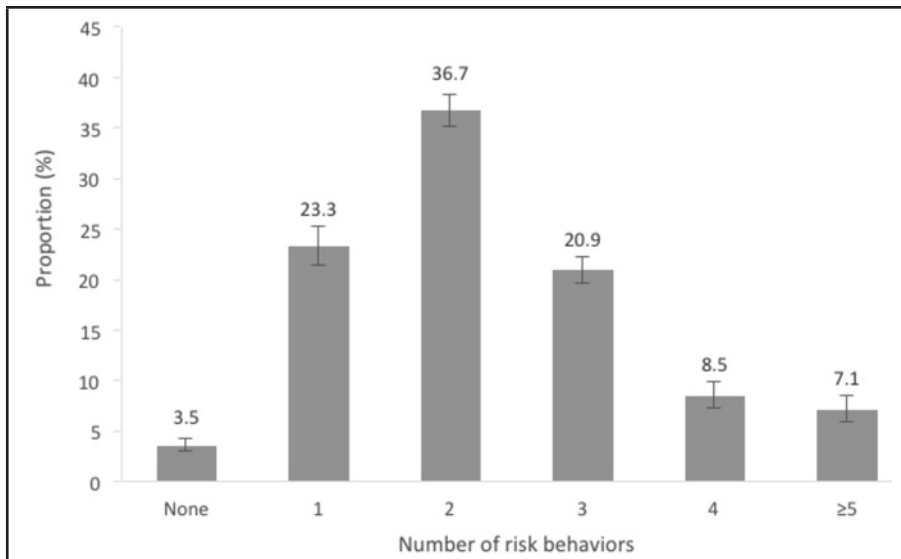


Figure 1. Distribution of Hawai'i public high school students with varying number of risk behaviors, Hawai'i YRBS, 2013, 2015. (Data subset to those with valid response data for all risk behaviors included in the risk behavior index.)

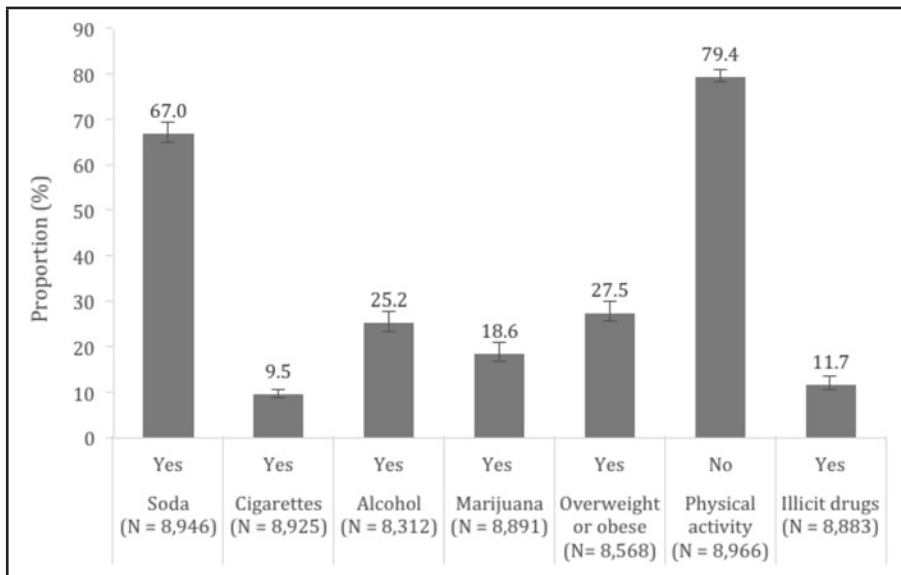


Figure 2. Overall prevalence of individual risk behaviors among Hawai'i public high school students, Hawai'i YRBS, 2013, 2015. (Proportion is out of total valid responses for each individual risk factor or risk behaviors.)

Table 2. Bivariate Analysis Between Age, Race/ Ethnicity, Sex, and Multiple Risk Behaviors with Dentist Visit in the Past 12 Months, Hawai'i YRBS, 2013, 2015 (N = 9,065).

	Dentist Visit in the Past 12 Months <sup>a</sup>		P-value <sup>d</sup>
	% <sup>b</sup>	95% CI <sup>c</sup>	
<b>Sex</b>			
Female	79.0	76.8—81.0	<.001
Male	75.4	72.9—77.7	
<b>Age (years)</b>			
≤14	79.8	75.3—83.6	.123
15	78.5	75.2—81.4	
16	77.2	74.1—80.0	
17	75.4	72.7—77.9	
≥18	73.8	68.7—78.3	
<b>Race / Ethnicity</b>			
Hispanic or Latino	66.3	57.5—74.1	<.001
Native Hawaiian	71.6	67.5—75.4	
Filipino	76.0	73.3—78.4	
Japanese	85.4	79.6—89.7	
White	83.3	78.0—87.5	
Other PI	64.0	59.1—68.7	
Some other race/ethnicity	78.7	72.8—83.6	
I do not describe myself as only one race or ethnicity	75.5	72.2—78.5	
<b>Number of Risk Behaviors</b>			
None	84.1	76.1—89.7	.026
1	81.7	77.6—85.3	
2	80.1	77.6—82.3	
3	79.3	76.2—82.1	
4	75.1	69.6—80.0	
≥5	74.0	66.6—80.2	
<b>Overall</b>	<b>77.1</b>	<b>75.1—79.1</b>	<b>N/A</b>

<sup>a</sup>Percent of students who visited the dentist in the past 12 months. <sup>b</sup>Weighted percentages, except for missing categories. Missing and unknown categories excluded from weighted calculations. <sup>c</sup>Confidence interval around the weighted prevalence estimate. <sup>d</sup>Chi square P-value.

Table 3. Association of Selected Characteristics<sup>a</sup> with Likelihood of Dentist Visit in the Past 12 Months, Hawai'i YRBS, 2013, 2015 (N = 9,065).

	Crude model		Final model <sup>b</sup>	
	Risk ratio	95% CI <sup>c</sup>	Risk ratio	95% CI <sup>c</sup>
<b>Sex</b>				
Female	1.00	(Referent)	1.00	(Referent)
Male	0.95	0.93—0.98	0.98	0.95—1.00
<b>Age</b>				
≤14	1.00	(Referent)	1.00	(Referent)
15	0.98	0.93—1.04	0.95	0.91—0.99
16	0.97	0.92—1.02	0.93	0.88—0.97
17	0.95	0.90—0.99	0.92	0.88—0.95
≥18	0.92	0.86—1.00	0.91	0.86—0.97
<b>Race / Ethnicity</b>				
Hispanic or Latino	0.80	0.70—0.91	0.88	0.79—0.97
Native Hawaiian	0.86	0.81—0.91	0.87	0.82—0.92
Filipino	0.91	0.86—0.97	0.92	0.87—0.97
Japanese	1.03	0.96—1.10	1.02	0.97—1.08
White	1.00	(Referent)	1.00	(Referent)
Other PI	0.77	0.70—0.84	0.82	0.75—0.89
Some other race/ethnicity	0.94	0.85—1.05	0.95	0.86—1.04
I do not describe myself as only one race or ethnicity	0.91	0.86—0.96	0.90	0.86—0.95
<b>Number of Risk Behaviors</b>				
None	1.00	(Referent)	1.00	(Referent)
1	0.97	0.89—1.07	0.97	0.89—1.06
2	0.95	0.88—1.03	0.95	0.88—1.03
3	0.94	0.87—1.02	0.96	0.88—1.04
4	0.89	0.82—0.97	0.91	0.84—0.99 <sup>d</sup>
≥5	0.88	0.80—0.97	0.90	0.82—0.99 <sup>e</sup>

<sup>a</sup>Selected characteristics includes variables that were significant in final logistic regressions model. <sup>b</sup>Final model: Logistic regression included age, sex, race/ethnicity, and number of risk behaviors. <sup>c</sup>95% confidence interval around the adjusted risk ratio. <sup>d</sup>Upper bound of confidence interval is 0.995. <sup>e</sup>Upper bound of confidence interval is 0.992.

income of \$75,000 or over compared Asians (39%) and Caucasians (40%).<sup>35</sup> The evidence for disparities across these groups warrants comprehensive investigation into upstream factors (eg, socio-economic and political structures) that adversely affect children of certain race/ethnicity throughout the life-course.

Although the association between risk behaviors and likelihood of dental visiting in this study was only significant for those with four or  $\geq$  five risk behaviors, our results are similar with those of Yang, et al, which found that US children with a greater number of social risk factors had increased odds of not having a dental visit.<sup>36</sup> Estimates in the overall prevalence of individual risk behaviors and among those with one, two, or three risk behaviors provide a possible explanation for non-significant associations in those with lower numbers of risk behaviors in our study. Non-adherence to physical activity recommendations, soda consumption, and overweight or obese status were the three most prevalent individual risk behaviors and constituted the most common combinations among those with one, two, or three risk behaviors. In addition, 78.5% of the study population belonged to categories having either one, two, or three risk behaviors. The high prevalence of non-adherence to physical activity recommendations, soda consumption, and overweight or obese status both individually and in combination suggests that different risk behaviors have disproportionate effects on oral health outcomes. Nevertheless, inclusion of all risk behaviors is beneficial to the analysis because the risk behaviors in question are accounted for. Considering that many of the health behaviors found in this study to adversely affect oral health also relate to nutritional status, this study reinforces Grossi, et al,'s proposal of integrating oral health screening, education, and treatment with measures addressing childhood obesity.<sup>37</sup>

Interestingly, despite racial/ethnic differences in oral health among Hawai'i subpopulations, most Hawai'i residents reported having adequate access to services and good oral health in the 2015 *Hawaii Oral Health: Key Findings* report.<sup>32</sup> This implies the need to look beyond the question of access to that of community and age-specific attitudes toward utilization of dental services as well as provider practices. Among Hawai'i children enrolled in Medicaid, 35% of Hawai'i children received dental treatment compared to 24% nationally.<sup>32</sup> The dental public health community acknowledges that high-risk populations may not be fully aware of the downstream advantages of preventive dental visiting;<sup>4,38</sup> however, oral health can serve as a window into an individual's overall health and is associated with various chronic conditions.<sup>39</sup> Presently, little has been published on best practices for increasing utilization of dental services among children in high-risk communities. More research in this area is needed because effective early intervention requires a better understanding of the oral health perspectives of both the child and caregiver at the community-specific level.<sup>40-42</sup>

Lastly, fluoridation in community water systems has long surrounded the discussion of oral health in Hawai'i. Fluoride is a naturally occurring mineral and several studies have shown that, regardless of mode of exposure, dental fluoride treatment

leads to nearly a 25% reduction in dental caries in children, adolescents, and adults.<sup>43-45</sup> Evidence of the safety and benefit to oral health conferred by water fluoridation has led many communities in the United States and worldwide to adopt the practice of adding fluoride to local drinking water at optimal levels to prevent tooth decay. Due to its high efficacy in reducing dental caries, the CDC has listed water fluoridation as one of the top 10 public health achievements of the twentieth century.<sup>46</sup> Nevertheless, 2014 data shows that only 12% of Hawai'i residents receive fluoridated water compared to 74% nationally.<sup>47</sup> Hawai'i's reluctance to adopt water fluoridation is reflected in poor oral health outcomes as demonstrated by the 2015 *Hawaii Smiles Report* and dental report cards published by the Pew Center on the States.<sup>7-9</sup> While the impact of water fluoridation in helping protect against specific risk factors and risk behaviors is not clear, the introduction of fluoridation to community water systems presents an untapped opportunity to improve oral health outcomes for all Hawai'i residents. Unlike the other risk factors and risk behaviors assessed in this study, lack of water fluoridation must be viewed through a population-based approach to etiology because it is homogeneously distributed across the entire population with the exception of military bases.<sup>8,48</sup> The desired result of introducing water fluoridation in Hawai'i is that the normal distribution representing Hawai'i's overall oral health status would shift in a favorable direction and lower the total number of individuals with poor oral health.

This study and its findings are subject to several limitations. First, the study relied on self-reported YRBS data, which is subject to both recall bias and social desirability bias, especially regarding questions over culturally sensitive risk factors and risk behaviors (eg, overweight/obese status, drinking, smoking, and drug use).<sup>49</sup> As a result, the prevalence of behaviors from the YRBS data may not be reflective of students' actual behaviors. Second, given the constraints of the YRBS questions, the question "When was the last time you saw a dentist for a check-up, exam, teeth cleaning, or other dental work?" served as a proxy indicator for oral health status, but is not indicative of an individual's or community's true oral health status. This was done in the absence of more detailed clinical information on oral health that is not recorded in the Hawai'i high school YRBS. Third, a large proportion (15.4%) of the original YRBS high school respondents were excluded from the analysis. This included 765 students (7.1%) who were missing data on dental service utilization and 890 students (8.3%) who were unsure when they last received dental services. Fourth, Hawai'i has a larger proportion of students who attend private schools than the rest of the nation. In 2015, an estimated 21.3% of Hawai'i students in grades 9 to 12 attended private schools compared to 9.6% nationally.<sup>50</sup> Ideally, we would like to capture a sample that is representative of all high school students in Hawai'i, but our estimates exclude students who attend private school because Hawai'i YRBS is only conducted among public schools. Further research is needed to directly compare the oral health status of private school students to public school students; however private school students are more likely to come from a high-income

family and children from high-income families are less likely to experience dental problems.<sup>32, 51</sup> Fifth, given the diversity of the risk factors and risk behaviors, we propose that future analyses consider including some determination of the relative impact of the individual risk factors and risk behaviors on oral health. Finally, the YRBS high school survey lacks questions on socioeconomic status (SES), which is associated with adverse oral health outcomes in adolescents.<sup>52, 53</sup> Including indicators of SES, such as questions on receipt of free or reduced lunch or homelessness could allow a way to partially control for SES and serve as a useful stratifier.

Adverse oral health outcomes can be targeted through screening of risk factors and risk behaviors, early recognition, treatment, and education. Immediate dental interventions may provide a temporary solution to poor oral health, but they do not address underlying risk factors and risk behaviors that precede disease such as race/ethnicity, consumption of food and beverages with high sugar content, smoking, lack of physical activity, and underutilization of dental services. Many determinants of oral health overlap with those of overweight/obesity; thus, integrating oral health programs with school health programs that aim to reduce overweight/obesity could lead to more efficient identification of at-risk students and a better return on investment of resources. Moreover, this study found race/ethnicity to be a risk factor in the likelihood of having a dental visit and provides a basis for identifying schools that have a large representation of racial/ethnic groups for which oral health disparities are known. This study emphasizes the need for developing programs tailored for increasing utilization of dental services among adolescents who are more susceptible to experiencing risk behaviors or belong to disparate racial/ethnic groups.

## **Disclaimer**

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Hawai'i State Department of Health.

## **Conflict of Interest**

None of the authors identify any conflicts of interest related to this publication.

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### Authors' Affiliations:

- Health Resource and Services Administration, Graduate Student Epidemiology Program; Rockville, MD (AE)
- Houston Health Department, Bureau of Epidemiology; Houston, TX (AE)
- Hawai'i Department of Health, Family Health Services Division; Honolulu, HI (DKH)
- Centers for Disease Control and Prevention; Atlanta, GA (DKH)
- University of Maryland, School of Dentistry; Baltimore, MD (SU)
- University of Hawai'i at Manoa, School of Nursing and Dental Hygiene; Honolulu, HI (DM)
- New York University – Lutheran Dental Medicine, Dental public health residency program; Honolulu, HI (JD)

### Correspondence to:

Alex Espinoza MPH ; 318 Richey Rd., Houston, TX 77090;  
Email: Alex.Espinoza@my.unthsc.edu

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# 2017 WRITING CONTEST GRADUATE WINNER

## Physical Activity & People with Disabilities — A Qualitative Process and Outcome Pilot Evaluation of the Non-Profit Organization AccesSurf Hawai'i

Simone M. Schmid MPH; Cara Troy Short; and Claudio R. Nigg PhD



Simone M. Schmid MPH

Simone Schmid is a PhD student in Public Health at the University of Hawai'i. She earned her MPH in London and an MA in Physical Activity and Health, and a BSc in Health Economics/Health Care Management in Germany. She has professional public health experience in health policy, research, evaluation, development cooperation, and management, gained at the United Nations and with non-profit organizations and the private sector in Hawai'i, England, Denmark, Germany, Singapore and Australia. Her goal is to connect academia and health practitioners to design applicable, research-based, innovative solutions addressing health behavior. She is especially keen to improve health equity by supporting disadvantaged population groups, including people with disabilities in Hawai'i. Her passion is research in physical activity.

Her winning manuscript is entitled "Physical Activity & People with Disabilities — A Qualitative Process and Outcome Pilot Evaluation of the Non-Profit Organization AccesSurf Hawai'i." A growing number of studies suggest that physical activity can maintain and improve the physiological and psychological well-being of people with disabilities. However, there are only a limited number of studies that have tested interventions to increase physical activity for people with disabilities. This manuscript presents findings from

a qualitative process and outcome evaluation of the non-profit organization AccesSurf Hawai'i. The mission of AccesSurf Hawai'i is to provide ocean-based, sports activities to help children and adults with disabilities and to wounded veterans discover their abilities in the ocean.

### Abstract

Physical Activity (PA) is essential for the prevention of non-communicable diseases (NCD). The risk of developing NCDs is three times as high among people with disabilities than people without disabilities. In 2016, an estimated 158,570 people in Hawai'i had disabilities. So far, only limited studies have considered increasing PA opportunities for people with disabilities. AccesSurf is a non-profit organization empowering people with disabilities to perform adaptive swimming and surfing. The purpose of this study was to conduct qualitative process and pilot outcome evaluation of AccesSurf. A focus group was conducted to explore the perspectives of six AccesSurf participants on AccesSurf's process, participants' outcomes, and suggestions. Participants were individuals with neurological health conditions, aged between 30 to 64 years. The analysis followed a deductive-inductive approach. Focus group participants reported on process variables, such as the positive environment and the provision of a range of PA opportunities (eg, adaptive swimming & surfing, stand up/outrigger/va'a paddling, kayaking, and surf skiing). They recognized AccesSurf's positive contribution to their physical, mental, and social health. Participants not only felt empowered through AccesSurf, but also increased their PA frequency and built athletic identities. A comfortable environment and provision of a variety of opportunities for participants were identified as advantageous AccesSurf outputs, fostering progressive short- and long-term outcomes that result in life-changing effects. This research shows that AccesSurf may play an important role towards increasing PA among participants.

### Keywords

Physical Activity, People with Disabilities, Neurological Impairments, Spinal Cord Injury (SCI), Adaptive Sports, Aquatic Exercise, Focus Group, AccesSurf Hawai'i.

### Introduction

As physical activity (PA) is declining, the burden of non-communicable diseases (NCDs) increases.<sup>1</sup> It is predicted that by 2020, seven of ten deaths will be caused by NCDs.<sup>2</sup> PA improves well-being<sup>3</sup> and quality of life (QoL),<sup>4</sup> and hence can reduce the existing NCD health burden and its risk factors. Despite the increase in PA promotion and efforts for the general population, there are limited options for people with disabilities to be physically active.<sup>3</sup> The Centers for Disease Control and Prevention (CDC) emphasizes that the World Health Organization's (WHO) PA guidelines are for everyone, including people with disabilities.<sup>5,6</sup> The CDC defines adults with disabilities as those "with serious difficulty walking or climbing stairs; hearing; seeing; or concentrating, remembering, or making decisions."<sup>5</sup> The risk of developing NCDs is three times as high among people with a disability compared to people without a disability.<sup>5</sup> Worldwide, about 15% of the population have some sort of health condition causing disability.<sup>7</sup> Within the United States (U.S.), about 21 million adults aged 18-64 years (6% of the total U.S. adult population) have disabilities with nearly half of these (11 million) engaging in no leisure time PA (PA outside of school and work).<sup>5</sup> In 2014, about 9% of Hawai'i adults had a mobility disability, 2% reported a self-care disability, and 6% required a device.<sup>8</sup>

Community-based aquatic activities for people with disability amongst U.S. adults<sup>9</sup> showed an increase in their QoL.<sup>11</sup> Aquatic



activities provide moderate aerobic PA,<sup>10</sup> and improve motor skills in people with disability.<sup>11</sup> Adaptive Surfing is a type of aquatic exercise described as novel physiotherapy that increases both inclusion in society and disability awareness.<sup>12</sup> AccesSurf (described in following paragraph) uses the term “adaptive” to refer to the act of modifying equipment and/or the way in which a person surfs to accommodate the skills/ needs of a participant with disability. Only a few studies on aquatic adaptive sport are available,<sup>13-17</sup> with two pilot studies investigating adaptive surfing.<sup>13,17</sup> Surfing is a sport performed discontinuously, with about 50% of the time spent paddling.<sup>18</sup> However, there is a lack of research on the effectiveness of adaptive sports, especially adaptive surfing, providing PA for people with disabilities.

AccesSurf ([www.accessurf.org](http://www.accessurf.org)) is an established and experienced non-profit organization, based on O’ahu, whose mission has been to “empower people with physical and cognitive disabilities through accessible water programs” since 2006.<sup>19</sup> To fulfill their mission, AccesSurf has established several free programs for participants that are mainly volunteer-run including Day-at-the-Beach (DATB) and Wounded Warrior DATB. DATB is the main monthly program run at their base location, White Plains Beach Park, on O’ahu. Each event assists up to 140 participants to perform ocean activities, such as floating, swimming, and surfing. The Wounded Warrior DATB is limited to participants who are affiliated with the military. Since 2014, AccesSurf added swim and surf clinics to their programs, which are run at different local pools and beaches. AccesSurf established an adaptive surf team in 2016. Duke’s Oceanfest is an annual month-long fest that consists of many competition days for a variety of ocean sports, including surfing, paddling, swimming, and others to honor Duke Kahanamoku, the Hawaiian water legend. The Hawai’i Adaptive Surfing Championships is a program of AccesSurf that has been held yearly since 2007 in collaboration with the Duke’s Oceanfest (also known as “Duke’s”) to offer a week-long elite adaptive surfing competition that highlights the international, national, and local adaptive surfing community.”

In 2016, AccesSurf provided 50 formal events with 1315 registered participants (having one to multiple water experiences per event) and 2795 registered volunteers. The set-up of all programs is not permanent. AccesSurf stores and brings all needed equipment to the beach, thus creating their slogan—an “Ocean of Possibilities.”<sup>19</sup>

The objective of this study was to provide a programmatic evaluation of AccesSurf’s adaptive surf program by examining organizational outputs and participant level outcomes.

## Methods

This is a qualitative programmatic analysis using a focus group design to evaluate the aquatic program by AccesSurf.<sup>20,21</sup>

The recruitment criteria included participants who had a neurological health condition and were regularly involved with more than one type of AccesSurf event. A focus group (FG) of six people was desired to include a diversity of participants and information provided, yet small enough to create

an environment where participants feel comfortable sharing their thoughts, opinions, beliefs, and experiences. Purposive and snowball sampling<sup>22,23</sup> were used to over-recruit by at least 20% of intended minimum participant numbers. Therefore, we planned to recruit eight individuals to have at least six FG participants.<sup>24</sup> AccesSurf’s Executive Director facilitated the initial introductions with selected candidates. Email invitations were sent to selected AccesSurf participants during August 2015.

Two guiding questions creating a comprehensive structure suggested by Gläser and Laudel<sup>25</sup> were combined with the four steps “gather, review, sort, order” method by Helfferich<sup>26</sup> to develop the FG guide. The FG guide was adjusted in collaboration with AccesSurf’s Executive Director after piloting it with an AccesSurf volunteer.

The meeting room used for the focus group was chosen because of its relaxed atmosphere and wheelchair accessibility. The FG set-up was a circle and refreshments and snacks were available. The FG was facilitated in September 2015, lasted 120 minutes and was recorded by four devices. The FG was transcribed and de-identified.

FG participants gave written and oral consent. The University of Hawai’i at Manoa (UH) Institutional Review Board approved this project. The FG transcription was coded using MAX QDA 12 (VERBI GmbH; Berlin; Germany)<sup>27</sup> software following a deductive-inductive approach. A mix of deductive and inductive<sup>28</sup> analysis approaches were used, especially because of the study’s evaluative purpose to identify and possibly conceptualize program process and outcomes.<sup>29</sup> A deductive approach is relatively narrow and top-down, using and applying a code system, based on a theory to the content.<sup>30</sup> An inductive approach allows for codes beyond preset categories. Therefore, we used a mix of both approaches to maximize the advantages of both,<sup>29</sup> having categories for orientation in mind, but not limiting the analysis to those. Five deductive categories were identified prior to coding and inductive “free coding” was used while coding (unlimited initial coding).<sup>31</sup> This combination allows the analysis to be rather more “explorative” and “open-ended” than a pure deductive approach.<sup>30</sup>

## Results

Eight out of eight program participants agreed to be in the FG, however, due to time constraints only six were able to participate (Table 1). They ranged in age from 30 to 64 years; 50% were women, and they participated at AccesSurf between 12 months to 10 years. Four participants had Spinal Cord Injury (SCI) and two had other forms of neurological health conditions. Participants had their conditions either from birth (one), or between seven to 44 years (five) (Table 1). All participants participated at the main event DATB, one also at the Wounded Warrior DATB, five participated at AccesSurf swim clinics, three participated in surf clinics, and all competed at Duke’s.

The main results based on the emerging theme categories gave insight into key participants’ perceived AccesSurf’s process, participants’ outcomes, and suggestions for AccesSurf. Overall, there are 12 main themes, with six total themes for

Table 1. Description of 2015 Focus Group Participants			
Participant Number	Neurological Health Condition Resulting in Motor Impairment	How Long Participated	AccesSurf Activities
P-1	Spinal Cord Injury (SCI) incomplete**	1 year	Surfing, Swimming; Competition, Volunteer committee
P-2	Charcot-Marie-Tooth (CMT)*	1.5 years	Surfing, Swimming; Competition
P-3	Quadriplegic**	1.5 years	Surfing; Competition
P-4	SCI T-4**	10 years	Surfing, Swimming; Competition
P-5	Spinocerebellar ataxia type 6*	1 year	Surfing, Swimming; Competition
P-6	Paraplegic*	> 3 years	Surfing, Swimming; Competition

Table 2. AccesSurf's Process and Outputs
<p><b>1) Positive atmosphere – AccesSurf organization and first-timers</b></p> <ul style="list-style-type: none"> <li>- 'AccesSurf is all about the 'Ohana' (...) you belong to something, to somewhere'.</li> <li>- 'It's just people like you, or some people worse than you, but they have the best smile on their faces (laughs), because of AccesSurf'.</li> <li>- '(...) Now, we have this whole network of people that talk to each other through Facebook or whatever. (...) There is this whole community, here, that I am part of.</li> <li>- '(...) there is a whole culture of surfing that we are now part of, and that has something to do (...) [with] having to prove ourselves'. 'AccesSurf makes it pretty darn easy. You just show up and get in [the water, surf, swim]'.</li> <li>- '(...) I came from XY you know, where a disabled person, is very looked down, and there is (...), there is nothing like AccesSurf, back home, where you feel like you relate to someone (...) whole time (...) I was isolated. (...) I was ashamed, I did not want anybody to look at me'.</li> <li>- 'I was always active, tried to stay physically fit, tried to swim laps, I was a lap swimmer, it was a very solitary activity, I was by myself and, guess, I had stopped, going to the beach, because it was hard to get in'.</li> <li>- 'I took a picture of it (...) you never see the handy van at the beach'.</li> </ul>
<p><b>2) Opportunities</b></p> <ul style="list-style-type: none"> <li>- 'We [surfers and especially with disabilities] are in this little tiny niche, and unless we get a chance to get together somehow, and I know internet helps, Facebook helped a lot but, this is the opportunity to see somebody like yourself and get inspired by them, because every disability is different. Everybody with a disability has a unique case, but you can come close, and then you can learn, from each other, I am sure there are things I can teach XY, but, he's definitely taught me some stuff, (...) that is the type of thing, that I would not have the opportunity without AccesSurf'.</li> <li>- '(...) I would say that getting into the ocean, is, oh gosh, I would go once a year down to (...), because they had a special day, (...) now, it is at least one day a week, a month with DATB, and then there's chances to go, with this surf team, adaptive surf team, that adds about two to three days a month I guess, and then on our own, we are going (...) every morning (...)'.  <li>- 'I had an old beater of it, that I used as a spare. That is when I went out and I bought wide tires (...). It was really, it was a good suggestion, they explained it (...) you have to have something to get over the stretch of sand here, and this is what we do. So I, learned from other people'.</li> </li></ul>
<p><b>3) Enjoyment and excitement: Fun</b></p> <ul style="list-style-type: none"> <li>- 'When is the next day?'. '(...) it is always so fun'; afterwards it was (...) so much fun (...)'.  <li>- '(...) it is more fun (...) and I really, I am enjoying the social part of it, too'.</li> <li>- '(...) as much fun, as we do'.</li> </li></ul>
<p><b>4) AccesSurf volunteers</b></p> <ul style="list-style-type: none"> <li>- 'It is like, so wonderful, and even the volunteers feel like, like they are so happy, to be there, so happy to help you, it gives them joy to help you'.</li> <li>- '(...) I feel comfortable, and the volunteers are over the top. And that's why I think, they volunteer there. None of them are getting paid, they do not have to be there, if they do not want to, they all choose to be there, and they all want to be there'.</li> <li>- 'I remember, driving to Waikiki [I] was terrified, I kept saying: "There is volunteers there, nobody is going to let you drown"'.</li> </ul>
<p><b>5) Natural settings and type of activity: Surfing</b></p> <ul style="list-style-type: none"> <li>- 'I think the type of sport that was picked, makes a whole big difference, because there's a lot of adaptive sport programs, but surfing has something special about it'.</li> <li>- '(...) recreation or whatever, in natural settings is like one of the most desirable settings to be in, with a disability, but also the (...) hardest setting to be in'; '(...) the goal, to have choice in natural settings and AccesSurf provides that into surfing. Because surfing cannot, well I guess it could be simulated, but simulated in those wave pools (...) it is not the same in surfing, you can be on the biggest part, these levels, these waves, you can be on the biggest wave and it is not the same as being on the smallest wave in Hawai'i in natural settings, there is a difference about that'.</li> <li>- 'There is a big difference between going into a pool, swimming pool, and swimming laps, where you basically set your own pace, you can push yourself or not push yourself, you have that choice. When you get into surf at White Plains and those waves are coming at you, you don't have any more choice, you are, you are in nature and nature is in charge and it pushes you really hard'. (...) You have to. It is like being on a water treadmill, and you do not get to set the pace, so it is a totally different thing, than any form of exercising (...) nature, is very powerful, and you have to deal [with it]'.</li> </ul>
<p><b>6) Duke's Oceanfest</b></p> <ul style="list-style-type: none"> <li>- 'Dukes, this year, on the Thursday, cause all we adaptive(s) [athletes] had the whole Queens for, what, 8 hours?'</li> <li>- 'My favorite moment was the, at Duke's Fest, when they had the awards and when they had us all, in front of that stage, and XX took that photograph of all of us together. That to me was amazing, the feeling of 'Ohana and togetherness, and just, we had accomplished that'.</li> </ul>

**Table 3. Participants' Outcomes and Effects**

<p><b>1) Immediate outcome</b></p> <ul style="list-style-type: none"> <li>- 'I have more freedom, cause, when I am walking, I got to hold my crutches, use my crutches, but once I get to the water, (...), I get on my board and (...) I paddle out and it is like, I am free. I do not have to worry about my crutches, or wheelchair (...).'</li> </ul> <p>Participants also reported on their enjoyment while participating, such as having fun:</p> <ul style="list-style-type: none"> <li>- 'I get to have just fun with all my friends out there, and we're not worrying about any disabilities, we are just out there having fun, catching waves (...).'</li> </ul>
<p><b>2) Long-term outcome</b></p> <p><b>a) Physical outcomes</b></p> <ul style="list-style-type: none"> <li>- 'I was not going to the beach, because I could not get in the water by myself'.</li> <li>- It helps me with transfers, I can transfer out of my regular tub (...) transfer is one, has definitely changed, and cause, we are transferring off the ground, we are transferring into different chairs, into our boats (...) and surfboards, we are doing a lot of transferring, and we are getting good at it'.</li> <li>- I am not bed-ridden like the neurologist said. It is not curing me, but it is prolonging my disability, where I can move and still be active'.</li> </ul> <p><b>b) Mental outcomes</b></p> <ul style="list-style-type: none"> <li>- 'It helped me with my social anxiety. I used to be, like even in this group, I used to fear sitting here and speaking talking to everybody. But going there [to AccesSurf], I see everybody, and [I] talk to different people, it made it easier, to keep going.'</li> <li>- (...) problem solving, finding the minds, I mean a lot of things, you become trained in (...) adaptability' (...) that is a positive thing, (...) I am involved, in the waveski or swimming with AccesSurf, that gives me inner good health, to be honest I have never been so healthy. (...) stronger, too'.</li> <li>- 'I kind of take that, philosophy and kind of apply that in my life, like, pursuing a doctorate in occupational therapy, or living out[side] of county, or whatever, things that I did. It repeats itself in all my life through all of those things, and AccesSurf was kind of the platform for me to jump into that, (...) I was able to apply that to other aspects of life'.</li> <li>- 'a platform you can launch off to be more independent' (...) 'Going by ourselves'</li> </ul> <p><b>c) Social outcomes</b></p> <ul style="list-style-type: none"> <li>- 'I feel like I have a much healthier relationship with my kids, and even with my family, because I am not always at home, I have something to look forward to'.</li> <li>- '(...) being that auntie that I am, I want to take all my nieces and nephews, which I have six of them, to surf and AccesSurf (...) made that possible. I was able to bring my nephew four times now, and I hopped in the water with him surfing, (...) and even my nephew with autism, which I would not be able to handle alone, (...) and even with my other nephew, who is older, who helps carrying me into the water, I am out there in the water surfing with him. And he is like that is my auntie. And you know he is super proud. (...) AccesSurf has made it so much easier for me to pass that love of the ocean down to my nieces and nephews (...), and may be even kids.'</li> <li>- '(...) when you go out to Queens break and you want to catch your wave, you got people there, they know what they are doing, they have been there a long time, and you better learn how to deal with them, too. So, it's a lot of, becoming part of the community (...).'</li> </ul>
<p><b>3) Effects</b></p> <p><b>Change, empowerment</b></p> <ul style="list-style-type: none"> <li>- 'I have an adult daughter and she's - it's sweet - she is very proud of me'.</li> <li>- 'I got a lot of stuff on my Facebook page, from people who knew me before [the injury; surfing], (...), and now, they see my surfing pictures on my [Facebook page], I get comments all the time.'</li> <li>- 'In getting stronger, getting more confident, may be not doing the tandem, may be, going on their own, or trying a new piece of equipment, they are doing more, where they get their own board (...) or you can hear stories of them, going out on their own.'</li> </ul> <p><b>Life-changing</b></p> <ul style="list-style-type: none"> <li>- 'I know my life, well, 12 months ago, was completely different, to what it is now, I was (...) And then I started surfing, and now today (...). Surfing has taken over my life, it's taking over my life cause I surf, I compete, I have some sponsors, I travel, I surf (...).'</li> <li>- That was a barrier for me, to just overcome that barrier of what happened, and AccesSurf made it a lot easier, and it broke that barrier (...); 'For me, I am getting out more by myself, in the ocean, the waveski (...) I get the coolest, I get recognized, because of the board, because of what I am going in the water with. For people to ask, what is that, it makes you like be happy to share; besides the team training, I get out in the water, two to three times in the week. Because I'm in the Hawai'i Team, going to represent (...).'</li> <li>- 'The experience at Duke's Fest is a transformation because you see people from all over the world. And I saw a guy, I didn't really think I can do wave skis, till I met XX. And he has a high level injury like I do, and I always felt like, oh well, you have a high level injury, forget it. I'm not gonna have the trunk stability, you're not gonna be able to control the board while you are going out and to be able to catch the waves. He has this method that he just parks his paddle when he gets on the wave, he grabs the board and he just muscled it (...) I would think I can do this, I am looking ahead now, I see hills in the distance I can climb, because of Duke's Fest'.</li> </ul>

process and AccesSurf outputs (three for process and three for outputs; Table 2), three for outcomes and effects (Table 3), and three for suggestions referred to as a “wish list.”

FG participants observed AccesSurf as an “*organization pretty big for this island*” [P-1] and for example as “*the best program, I have ever been involved with*” [P-2], where they “*cannot wait for the next time*” [P-2] (Table 2). FG participants perceived certain activities, emerged in six themes, as important factors during AccesSurf events and process, which can be considered as AccesSurf output(s). As shown in Table 2, these themes are the following: (1) Positive atmosphere – AccesSurf organization and first-timers; (2) Opportunities; (3) Enjoyment of and excitement about AccesSurf: Fun; (4) AccesSurf volunteers; (5) Natural settings and type of activity: Surfing; and (6) Duke’s.

Half of the FG participants declared an experience at Duke’s as their favorite moment [P-1, P-2, P-5] and several participants especially liked that their activities were photographed, which was expressed in comments like “*we have a picture*” [P-6] and “*we documented it*” [P-1]. P-2 and P-1 emphasized that Duke’s is an event where you can meet idols of adaptive athletes. (Table 2; Figure 1).

Three main participant outcome themes emerged: (1) Immediate and (2) Long-term physical, mental, and social outcomes, and (3) Effects (Table 3). All participants felt immediate outcomes, from the first time they participated and each time they returned. Advantageous opportunities provided by AccesSurf are, for example, the option to participate, getting to the beach and into the water, support for water activities, to experience

freedom in the water versus the land environment, making equipment and expertise available beyond actual events, having fun, and relating to other participants and volunteers. There was agreement amongst all participants that they feel 'different' before and after they participate in an AccesSurf event, such as a DATB [P-1 to P-4]. This was very clearly expressed by the phrase 'Every time!' [P-4]. P-5 whose only way of moving around on land is using crutches, reported an instant feeling of "being free."

All six FG participants reported as long-term outcomes that their physical, mental, and social well-being and health, have improved since participating at AccesSurf (Table 3). FG participants reported that they improved their strength, endurance, and flexibility. Before participating at AccesSurf they were either unable to enter the water or had a very hard time to do so and now they can enter the water. Thus, AccesSurf not only provides the opportunities to help with water transfer at event days, it helped FG participants to learn to access the water outside of AccesSurf. They claimed that their participation also improved daily activities outside of AccesSurf, such as transfers, and walking with fewer walking aids. For example, P-6 stated "When I first joined AccesSurf I used two crutches (...)," but reported since participating at AccesSurf, she reduced her use of walking aids to one crutch instead of two. P-5 is also convinced that AccesSurf helped him to fight his diagnosis by delaying the worsening of disease symptoms. Beyond physi-

cal improvements, one participant [P-2] called AccesSurf her "mental health", while other participants described a decline in social anxiety [P-5] and stress [P-6], and an all participants agreed on increase in self-confidence and independence. For example, P-2 is no longer embarrassed to crawl into the water, stating "AccesSurf is giving me the courage to say "yes, I can do it (...)." The translation of this 'can-do-it' mindset and increased self-confidence in other areas of life was also conveyed by a participant who reported replacing her shower with a bathtub [P-4].

Participants explained how they implement what they learned at AccesSurf in their lifestyle. AccesSurf helped participants with their relationships within their families, friends, and among the community (social outcomes). Participants also reported changes that family or others observed in them as well as change they see in others. Participants reported that their families were proud of them (effects) and that "My life was the same, it's just now I'm including surfing, which is a life-changer" [P-4]. The comment, "It's like, every time you do it, it gets better, it gets easier" [P-2] can be considered for each sub-theme as well as collectively. Coming to an event, participating and the activity itself gets physically and mentally easier with each practice.

Long-term outcomes and effects, such as change, empowerment, and life changes including motivation requires a participant to be a returning participant (Table 3; Figure1).

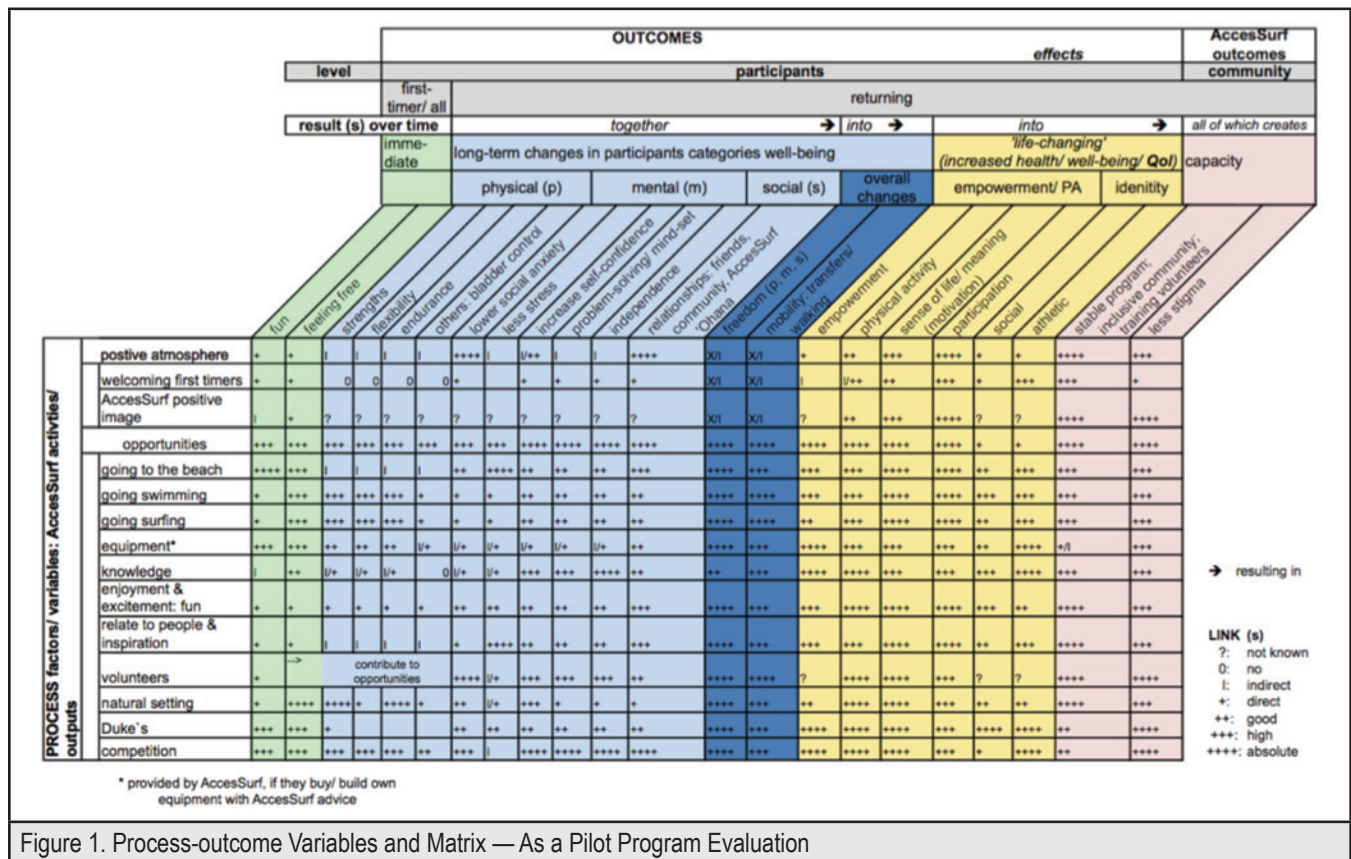


Figure 1. Process-outcome Variables and Matrix — As a Pilot Program Evaluation

The participants' wish list were divided into three categories: (1) Extension within existing programs for AccesSurf in general and in clinic (eg, training family members and caregivers), and DATB (eg, buddy-system, adding canoe); (2) Extension beyond existing programs, including location such as other beaches and islands; and (3) Outreach such as promotions about AccesSurf at schools.

While the intention was to present the process and outcome variables separately, they overlap. Figure 1 is a matrix of the reported process (vertical) (Table 1) and outcome (horizontal) variables (Table 3). It aims to visualize the relationship between both. Putting the variables of participants' perceived AccesSurf processes in relation to the outcomes (immediate and long-term) the following relationship(s) can be anticipated. There is either no direct link (0), there is an indirect (I) or a direct link (+) with different intensity: (++) good, (+++) high and (++++) absolute, or not given (?). Repeated participation can result (→) in overall changes (freedom and mobility) and effects that are life-changing: Empowerment/PA (empowerment, increase in PA, sense of life/meaning/participation), identity (social and athletic), and capacity (inclusive program and stigma reduction). Athletic identity was not considered in the original concept of this research question; it arose from the discussion as an important outcome and is therefore included here, and the same principle applies for stigma. Factors considered as AccesSurf outcomes are changes that participants mentioned relating to improvements within the community and not the individual participant level. This framework can help structuring and deepening future findings within the effects of adaptive surfing.

## Discussion

This study evaluated the process, outcomes, and recommendations of an aquatic program for individuals with disabilities in Hawai'i.

### Process and Outputs

Participants enjoyed being at AccesSurf events, spoke very highly of AccesSurf, were very appreciative of the service, and hesitant to voice any suggestions as it could be received as critique. Together, the atmosphere and opportunities for volunteer support and access to equipment, provided a positive experience for participants. The natural settings of AccesSurf venue(s) enhanced the benefits. For most participants, their first time at AccesSurf and Duke's were very meaningful events. Coming to AccesSurf has opened up a new world for participant where there are people like 'them', having fun and being happy, and wanting to return to AccesSurf. At Duke's, they not only related to others and became inspired by adaptive athletes, but they also competed and had a sense of belonging to AccesSurf and its 'Ohana (family). Duke's is strongly linked with the life-changing theme. The way participants presented both themes, Duke's and life-changing, underline an athletic identity as being salient to the participants.

### Outcomes and Effects

Participants also reported on their improved elements of well-being and overall changes through participating at AccesSurf. Having fun and "feeling free" are immediate participant outcomes, whereas physical, mental, and social long-term outcomes are experienced through repeated participation at AccesSurf. Participants reported physical improvements such as strength, endurance, flexibility, and bladder control. Mental improvements mentioned were lower anxiety and stress, greater self-confidence and independence. The feeling of greater independence could be due to improvements in all elements of well-being. Social well-being was described as having been increased through building and improving relationships. AccesSurf has helped participants to "fulfill" their social role as an aunt or mother, while building new friendships and becoming part of the AccesSurf 'Ohana. As a result of physical, mental, and social improvements, participants experience change(s) in themselves and others. Participants experience greater freedom in multiple ways and mobility improved by either enhanced transfer skills or walking ability, needing fewer walking aids.

Effects were outcomes that had a "life-changing" impact. Whereas some experiences might be fun and life-changing during the early stage of participating at AccesSurf, overall a participant needs to not only return to AccesSurf, but to become a regular and core participant to gain maximum benefit for their well-being and health. One perceived change and one effect are freedom and empowerment. Freedom is created by AccesSurf from lower to higher levels, for example, from the instant feeling of freedom on entering the water without a wheelchair or crutches, to a sense of freedom overall. The sensation of feeling free is reinforced by the increase in physical and mental strength, AccesSurf support, and they experience an enhanced sense of freedom through the feeling of empowerment. Empowerment is understood by Page & Czuba as a multi-dimensional social process helping to increase the control over their own life.<sup>32</sup> FG participants have the strong belief that they and others were empowered through AccesSurf, not only by participating in AccesSurf events but also by attending events outside of AccesSurf in groups or even by themselves, which provides freedom of choice. AccesSurf also provides knowledge through experienced staff, volunteers, and other participants on equipment and best sample practice on programming.

FG participants reported being more active and motivated than before their participation in AccesSurf. Surfing counts as a moderate physical activity.<sup>7</sup> Others argue that surfing is a vigorous physical activity due to the natural setting and to the heart rates achieved during paddling.<sup>33</sup> Frequent adaptive surfers meet the PA guidelines to be sufficiently active.<sup>34</sup> As reported by the FG participants, adaptive surfing helps them with their physical and mental well-being, and it may prevent secondary diseases, especially NCDs, which have a higher prevalence amongst people with disability due to lower activity.<sup>5</sup>

Our study design cannot answer which came first: the increased inclusion or the physical activities component. The fact is that they not only benefit each other, but also improve QoL.

McVeigh and colleagues<sup>35</sup> found that participation in sports after SCI significantly correlated with increased community integration and QoL. During AccesSurf events, participants can meet and relate to one another, and build friendships and support groups. AccesSurf strengthens community integration and improves QoL. Similar to our results, increased QoL was also found by two other studies not limited to SCI.<sup>10,16</sup> They found increased QoL within adults with disabilities participating in community-based aquatic activities and that adaptive sport programs positively improved family, social life, QoL, and overall health. Further research should investigate if the benefits are with QoL overall, or with sub-domains of QoL, namely environmental, psychological, and social relationship domains.<sup>14</sup>

The positive results were associated with reduced anxiety, which was also described by our FG participants. It was further reported that programs including family members increase the quality of family life. AccesSurf participants reported that family life improved not only for those whose family participated in the program, but also for those who participated by themselves. The results align with adaptive sport programs in general, and Lopes<sup>12</sup> who claimed that surfing helps with physical, mental and social rehabilitation, empowerment, and social integration. In the Lopes study, the limiting factor was the number of events per year, which was reported as five. AccesSurf provides more than twice as many events for everyone each year, with additional events for certain groups.

While Kissow<sup>35</sup> did not find any evidence that learned aspects of sport participation can be transferred to other contexts of life, FG participants reported that they were able to use what they learned through AccesSurf in their personal lives, such as a positive mind-set and self-confidence, allowing them to travel. One participant reported that she moved off island and out of the country for some time. Although surfing is an individual sport, participants reported the same benefits as team sports,<sup>37</sup> due to the setting of AccesSurf and its inclusive community counteracting stigma. Participants had been suffering from isolation and negative stigma, whereas now they felt part of the AccesSurf 'Ohana, where everyone is treated equally.

The high involvement of FG participants in AccesSurf, led to them discussing and mentioning aspects of the team, Duke's and life-changing, which led to the concept of identity, and ultimately athletic identity. All participants are returners and considered as not only regular but core participants, but this was not a recruitment criterion and happened by chance. It emerged within the analysis that all participants are athletes, as they all compete. AccesSurf enhances factors for building, regaining or strengthening identity, such as choice, freedom, and social inclusion.<sup>37</sup> Gill emphasizes the strong connection to integration within identity development.<sup>38</sup> Participants reported gaining freedom on different levels through participating at AccesSurf. Furthermore, it is a stable platform providing freedom and hope, which are important factors for identity. Overall participants reported that they gained their identity through activities such as performing sports, travelling, studying, and working. Ac-

cesSurf provides options for being physically active, and also for becoming an athlete. Individually or together, these options can be considered as giving participants a purpose. Athletic identity is an essential factor assisting in the adjustment and dealing process.<sup>37</sup> Hawkins also emphasized that rehabilitation and participation in sport should aim to directly build on, for example, a person's pre-injury athletic identity.<sup>37</sup> Thus, starting adaptive sports should be done as early as possible. However, with an acquired health condition such as SCI, trauma needs to be considered. Tasiemski and Brewer report on low and high athletic identity.<sup>39</sup> The trend towards an increased athletic identity through AccesSurf is evident in all participants, and is potential for further research. For example, participants acknowledged increased athletic identity by referring to themselves as adaptive (independent) surfers, their involvement with surf competitions (Duke's), the team, and the experience as life-changing events. It was important to them that their achievements and successes were documented by pictures, which was meaningful to all of them. All these elements help to build athletic identity.<sup>38</sup> The wish-list item of more coaching for themselves and others, shows how much they want to strengthen their own athletic identities and those of other AccesSurf participants. Tasiemski and colleagues<sup>40</sup> not only refer to athletic identity in people who perform sport on a competitive level, they also refer to it to people who participate in sport regularly. Therefore, athletic identity might be developed in more than the competitive participants. This needs further investigation within AccesSurf; it would be very beneficial to participants, as athletic identity is known to be more empowering than disability identity,<sup>36</sup> and can facilitate a life-long adjustment to disability.<sup>37,38</sup>

### Participants Wish List

Participants were reluctant to make suggestions for improving AccesSurf. It was only once the suggestions were called a "wish list" that participants slowly started to make recommendations.

One suggested *wish* was that AccesSurf facilitate more freedom and empowerment by going to different beaches or having a permanent location. Familiarization with a new beach within an AccesSurf event not only makes it accessible for one event, but "opens" that venue for independent usage. Having a permanent location such as a clubhouse or a storage facility close to the coastline where they could store equipment and go surfing independently without having to bring equipment, had immense meaning for participants, fulfilling the *wish* for a 'home base' would facilitate being amongst peers more often.

### Strengths and Limitations

A strength of this study is its qualitative approach which enabled the exploration of participants' perspectives. The use of the software MaxQDA allowed for a more thorough and systematic analysis. With six participants and a duration of two hours, the FG is considered well-designed.<sup>41,42</sup> A balance of heterogeneous and homogeneous elements is suggested for FGs<sup>24</sup>. The FG participants were a homogeneous group in terms of being AccesSurf participants and having a neurological health condition resulting

in disability, which may limit generalizability. However, they were heterogeneous regarding their age, gender and effects of the health condition on for example the type and level of motor impairments. The setting and environment were appropriate,<sup>43</sup> and multiple recording devices in different locations ensured accuracy of reporting the FG discussions.

Qualitative methods are specifically appropriate for evaluation where program processes and outcomes are general, or not defined.<sup>29</sup> This is the case for AccesSurf, where overall goals are unspecific, and detailed goals need to be determined for future evaluation purposes.

The collaboration with AccesSurf allowed additional insight into community-based adaptive aquatic sports. It also supported identification of and access to participants to describe their different perspectives. The involvement and attendance of the Executive Director was advantageous in accessing participants' perspectives. Researcher bias due to a pre-existing collaboration with AccesSurf and participants speaking "for their organization" also may have introduced social desirability and some researcher analysis bias. Generalizability is limited due to the small number of individuals participating and the characteristics of the participants who all became competitive surfers and the use of only one FG. Conducting additional FGs would have resulted in higher quality; however, personnel resources were limited. The results need to be treated with caution, and confirmed, especially for participants with recent onset of disability.

### Recommendations

Factors and areas emerged from this study are possible parameters for future evaluation purposes to not only identify, but also create and implement research-based outcome measures for adaptive sports and surfing, also as a tool for inclusion. Within research it is important to visualize the need for research and exchange between researchers and representatives of local communities with the focus on people with disabilities and adaptive program designers.

### Conclusion

A comfortable environment and provision of a variety of opportunities for participants were identified as advantageous AccesSurf outputs, fostering progressive short- and long-term outcomes that result in life-changing effects. There is a strong belief amongst FG participants that participating at AccesSurf has improved their mental, physical, and social well-being. The FG participants not only feel empowered through AccesSurf in multiple dimensions, but have also increased their PA level in terms of frequency and built athletic identities. The study shows that programs such as AccesSurf can play an important role towards improvement within PA for people with neurological health conditions resulting into disabilities in Hawai'i, while also creating an inclusive community and counteracting stigma.

### Conflict of Interest

None of the authors identify any conflict of interest.

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### Authors' Affiliations:

- Office of Public Health Studies, University of Hawai'i at Manoa, Honolulu, HI

### Correspondence to:

Simone M. Schmid MPH; Email: [sschmid@hawaii.edu](mailto:sschmid@hawaii.edu)

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# Level of Recommended Heart Attack Knowledge among Native Hawaiian and Pacific Islander Adults in the United States

Holly Felix PhD; Marie-Rachelle Narcisse PhD; Brett Rowland MA; Christopher R. Long PhD; Zoran Bursac PhD; and Pearl A. McElfish PhD

## Abstract

*In this report we examine the level of knowledge about heart attack symptoms and what action to take if a heart attack is suspected among Native Hawaiian and Pacific Islander (NHPI) adults in the United States using data from the 2014 NHPI-National Health Interview Survey. Analyses include summary statistics to describe levels of heart attack knowledge and multivariate logistic regression to identify characteristics associated with having the recommended heart attack knowledge. Less than half (44.4%) of NHPI adults have the recommended heart attack knowledge. Significant differences in knowledge levels were found based on age; those aged 45-64 years and those aged 65 years and older were 68% and 78% more likely, respectively, to have the recommended heart attack knowledge compared those aged younger than 45 years. The level of recommended heart attack knowledge among NHPI is lower than that of the general population. Improving the heart attack knowledge of all Americans should continue to be a national priority, but efforts to target this group for heart attack knowledge improvement should be made given their high risk for heart attack.*

## Keywords

*Native Hawaiians and Pacific Islanders; heart attack; symptoms; National Health Interview Survey*

## Introduction

Each year, nearly 800,000 Americans experience a heart attack, 16.7% of which result in death.<sup>1</sup> The Centers for Disease Control and Prevention (CDC) have reported that Native Hawaiians and Pacific Islander (NHPI) adults have a higher rate of coronary heart disease, angina, and history of heart attack than white persons (6.0% vs 5.4%, respectively).<sup>2</sup> Native Hawaiians are 10% more likely to die of a heart attack than white persons.<sup>3</sup>

Research clearly documents that knowledge of heart attack warning signs and symptoms can prompt action to seek treatment in a timely manner and reduce mortality among those experiencing heart attacks.<sup>4</sup> Rapid treatment of heart attacks has been shown to reduce 30-day mortality from heart attack by 37%.<sup>5-7</sup> As a result, improving the public's "recommended heart attack knowledge" is a national priority.<sup>8</sup> Recommended heart attack knowledge includes knowing the five major signs and symptoms of a heart attack (pain or discomfort in the jaw, neck, or back; feeling weak, lightheaded, or faint; chest pain or discomfort; pain or discomfort in the arms or shoulder; and shortness of breath) and knowing to call 9-1-1 if they suspect a heart attack.<sup>9</sup>

Although improvements in knowledge levels have been observed from 2008 to 2014, a recently published analysis of 2014 National Health Interview Survey data indicate less than half of adult Americans (47.2%) have the recommended

heart attack knowledge, and disparities in this knowledge exist based on gender, age, educational levels, and race.<sup>9</sup> Specific to race, more white Americans (51.7%) have the recommended knowledge compared to blacks (42.9%), Hispanics (36.1%), and Asians (28.2%).<sup>9</sup>

Historically, health and sociodemographic statistics NHPI have been aggregated with persons of Asian heritage, thereby masking differences that exist between these two distinct racial groups and preventing appropriate adaption of public health interventions for cultural competence.<sup>10</sup> Acknowledgement of those significant differences led the National Center for Health Statistics to field the NHPI-National Health Interview Survey (NHIS) in 2014, through which 3,000 households with at least one NHPI member participated. Key findings from that survey show a significantly higher disease burden among the NHPI population subgroup compared to Asians alone and the United States (US) population as a whole,<sup>2</sup> and warrant the need for continued publication of health statistics specifically on NHPI persons. Therefore, to complement recently published data on the levels of recommended heart attack knowledge among adult Americans,<sup>9</sup> we present findings from an analysis of data from the 2014 NHPI-NHIS.

## Methods

### Data

As noted above, 2014 NHPI-NHIS data were used for our cross-sectional study. The questionnaire used for NHPI-NHIS was based on the NHIS general population survey questionnaire. A complex-stratified-multistage-area-probability design was used when the NHPI-NHIS was fielded to ensure the sample was representative of the non-institutionalized adult US NHPI population. Completed details on the NHPI-NHIS methodology are available in another publication.<sup>11</sup>

### Study Population

The study population consisted of 2,172 adults (age  $\geq 18$  years) who self-identified as NHPI alone (51%) or NHPI in combination with one or with more other racial identities but who reported NHPI was their primary race (49%). The NHPI-NHIS public use files do not include data to allow for the identification of specific NHPI racial groups (eg, Native Hawaiians, Samoans, Chuukese) or specific location of residence. Therefore, results are limited to representing the adult US NHPI population who are fully or primarily NHPI.

## Measures

The outcome of interest was recommended heart attack knowledge, which includes knowledge of five heart attack symptoms and knowing what to do if a heart attack is suspected. To determine knowledge of heart attack symptoms, respondents were asked, "Which of the following would you say are the symptoms that someone may be having a heart attack: Pain or discomfort in the jaw, neck, or back; Feeling weak, lightheaded, or faint; Chest pain or discomfort; Pain or discomfort in the arms or shoulder; and Shortness of breath." To determine knowledge of best action to take if a heart attack is suspected, respondents were asked to select one answer from a list of possible actions. Dummy variables were created to indicate whether respondents correctly identified the correct symptom and action. A summary variable was created which summed the number of symptoms and action the respondents correctly selected (range 0-6). A dummy variable was created to indicate whether a respondent had the recommended heart attack knowledge (summary variable score = 6) or not (summary variable score < 6).

The following characteristics were used to describe the survey population and used as predictors of having the recommended heart attack knowledge: female gender, age group (18-44 years, 45-64 years, ≥65 years), educational level (less than a high school education, high school graduate or equivalent, some college or college graduate), medical provider diagnosed history of coronary heart disease, and medical provider diagnosis of heart attack or angina.

## Analysis Plan

We used summary statistics (frequencies and proportions) to describe levels of knowledge of heart attack symptoms by select sociodemographic characteristics. We also applied a multivariate logistic regression model to identify characteristics associated with recommended heart attack knowledge. Estimates were weighted to account for complex sampling design features (sampling weights and stratification) and to provide an unbiased representation of the adult NHPI population living in the US. Associations were considered significant at the alpha level of 0.05. Analyses were completed using Stata v.15.1 (Stata Corp, College Station, TX).

## Results

The study population consisted of 2,172 adult NHPIs, but application of sampling weights and other design features in the analysis allows generalizability to the adult US NHPI population. The NHPI population is evenly divided by gender (50.1% female), but as a group is relatively young, with 61.2% being 18-44 years of age and only 9.3% being 65 years of age and older. Most NHPI persons have at least some college education (50.2%) and only 10.2% have less than a high school education. Three out of every 100 NHPI persons has a history of coronary heart disease, while two out of 100 has a history of heart attack or angina (Table 1).

Overall, 44.4% of NHPI persons had the recommended heart attack knowledge. Of the heart attack symptoms, nearly

all NHPI persons know that chest pain is a symptom of heart attack (91.1%), while they were least likely to know that pain/discomfort in the jaw, neck, or back is a sign of heart attack (54.7%). Nearly all NHPI persons know that the best action to take if a heart attack was suspected was to call 9-1-1 (94.7%) (Table 1).

In the regression model, controlling for the demographic characteristics and history of heart-related health conditions, we observed significant differences in knowledge levels based on age. NHPI adults aged 45-64 years were 68% more likely, and NHPI adults aged 65 years and older were 78% more likely, to have the recommended heart attack knowledge compared with NHPI adults younger than 45 years of age. We did not find statistically significant associations between sex or educational attainment and having the recommended heart attack knowledge. Similarly, having a history of coronary heart disease or heart attack/angina was not significantly associated with likelihood of having the recommended heart attack knowledge (Table 2).

## Discussion

Having the recommended heart attack knowledge is critical for optimal outcomes associated with heart attack. Quick recognition of heart attack symptoms and quick action to obtain treatment if a heart attack is suspected can reduce the risk of complications and mortality.<sup>5-7</sup> We found that less than half (44.4%) of NHPI adults living in the US have the recommended heart attack knowledge, that is they know all five signs/symptoms that a heart attack may be occurring and know to call 9-1-1 if a heart attack is suspected. This level of knowledge is lower than that of the adult US population as a whole (47.2%) and that of white persons (51.7%), but is higher than the level of knowledge among blacks (42.9%), Hispanics (36.1%), and Asians (28.2%).<sup>9</sup> In terms of predictors of recommended heart attack knowledge, we found that older NHPI persons (≥45 years) were significantly more likely than younger NHPI persons (18-44 years) to know all of the signs and symptoms of a heart attack and what to do if they suspect a heart attack is occurring, after adjusting for other demographic characteristics and heart-related conditions. No other characteristics, including having a history of heart attack/angina, were associated with having the recommended heart attack knowledge.

Although the level of heart attack knowledge across all racial/ethnic groups in the US needs improvement, it is particularly important that this knowledge level be improved among NHPI persons, given their higher likelihood of having coronary heart disease, heart attack, angina, and other health conditions that elevate the risk of heart attack, such as obesity and diabetes.<sup>2,3</sup> A review of the research literature did not identify any heart attack knowledge improvement interventions specifically targeting NHPI persons. However, several potential educational interventions were identified: (1) a 10-15 minute educational session delivered by health professionals to female patients visiting clinics in Northern California;<sup>12</sup> (2) an eight week class offered to interested participants in senior centers in Georgia;<sup>13</sup> and (3) a community-wide public education trial.<sup>14</sup> All showed

Table 1. Characteristics and Level of Recommended Heart Attack Knowledge among Native Hawaiian and Pacific Islander Adults Residing in the United States, Overall and by Select Characteristics																								
	Total						Pain or discomfort in the jaw, neck, or back						Feeling weak, lightheaded, or faint						Chest pain or discomfort					
	unweighted		weighted				unweighted		weighted				unweighted		weighted				unweighted		weighted			
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
<b>Total</b>	2172	100	590,460	100	1,320	60.8	321,673	54.7	1,678	77.3	434,192	73.8	1,992	91.8	535,873	91.1								
<b>Sex</b>																								
Male	1,026	47.2	294,112	49.9	592	57.8	145,360	49.8	785	76.6	203,993	69.9	941	91.9	266,262	91.2								
Female	1,146	52.8	296,348	50.1	728	63.5	176,313	59.5	893	77.9	230,199	77.7	1,051	91.7	269,611	91.0								
<b>Age group</b>																								
18-44 years	942	43.4	361,370	61.2	497	52.8	176,724	49.2	731	77.7	263,786	73.5	871	92.6	329,253	91.7								
45-64 years	833	38.4	173,929	29.5	553	66.5	109,964	63.2	632	76.0	128,541	73.9	766	92.1	159,070	91.5								
≥65 years	397	18.3	55,161	9.3	280	68.0	34,985	63.4	315	79.4	41,865	75.9	355	89.4	47,550	86.2								
<b>Educational level</b>																								
Less than high school	218	10.0	59,931	10.2	113	51.8	29,126	48.6	148	68.0	40,307	67.3	185	84.9	50,671	84.6								
High school graduate	747	34.4	233,958	39.6	448	60.0	121,162	51.8	579	77.5	171,210	73.2	684	91.6	212,920	91.0								
At least some college	1,207	55.6	590,460	50.2	759	63.0	171,385	58.2	951	78.9	222,675	75.7	1,123	93.2	272,282	92.5								
<b>Health conditions</b>																								
History CHD	119	5.5	19,637	3.3	87	73.1	13,036	66.4	98	82.4	16,100	82.0	109	91.6	18,280	93.1								
History AMI/Angina	73	3.4	13,563	2.3	52	71.2	8,220	60.6	58	79.5	9,831	72.5	64	87.7	11,656	85.9								
Call 911																								
Know all recommended heart attack knowledge																								
Shortness of breath																								
Pain or discomfort in the arms or shoulder																								
unweighted		weighted				unweighted		weighted				unweighted		weighted				unweighted		weighted				
n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	
1,825	84.1	467,779	79.5	1,880	86.6	499,003	84.8	2,067	95.3	556,876	94.7	1,098	50.6	261,240	44.4									
855	83.5	233,849	80.1	883	86.2	247,613	84.8	978	95.5	276,548	94.8	505	49.3	120,237	41.2									
Female	970	84.6	233,300	78.9	997	87.0	251,390	84.8	1,089	95.0	280,328	94.6	593	51.8	141,003	47.6								
<b>Age group</b>																								
18-44 years	765	81.3	273,961	76.3	821	87.3	306,888	85.5	902	95.9	339,765	94.7	420	44.6	141,870	39.5								
45-64 years	728	87.5	148,940	85.7	721	86.7	146,997	84.5	792	95.2	166,019	95.5	449	54.0	90,464	52.0								
≥65 years	332	83.6	44,878	81.4	338	85.1	45,118	81.8	373	94.0	51,092	92.6	229	57.7	28,906	52.4								
<b>Educational level</b>																								
Less than high school	164	75.2	47,745	79.7	178	81.7	48,779	81.4	202	92.7	55,751	93.0	92	42.2	23,438	39.1								
High school graduate	620	83.0	182,234	77.9	643	86.1	192,277	82.3	715	95.7	222,127	94.9	370	49.5	99,941	42.7								
At least some college	1,041	86.4	237,800	80.8	1,059	87.9	257,947	87.6	1,150	95.4	278,998	94.8	636	52.8	137,861	46.8								
<b>Health conditions</b>																								
History CHD	106	89.1	18,269	93.0	104	87.4	17,494	89.1	109	91.6	18,185	92.6	70	58.8	9,610	48.9								
History AMI/Angina	63	86.3	12,009	88.5	62	84.9	11,563	85.3	67	91.8	12,575	92.7	43	58.9	6,203	45.7								

Data Source: Native Hawaiian and Pacific Islander National Health Interview Survey, 2014.

Note: CHD=coronary heart disease; AMI=acute myocardial infarction.

**Table 2. Predictors of Recommended Heart Attack Knowledge among Native Hawaiian and Pacific Islander Adults Residing in the United States, by Select Characteristics†**

Respondent Characteristics	Odds Ratios‡	95% Confidence Intervals
<b>Sex</b>		
Male	—	
Female	1.26	(0.96-1.66)
<b>Age group</b>		
18-44 years	—	
45-64 years	1.68**	(1.16-2.42)
≥65 years	1.78*	(1.28-2.49)
<b>Educational level</b>		
Less than high school	—	
High school graduate	1.27	(0.74-2.19)
Some college/college graduate	1.47	(0.96-2.23)
<b>Health conditions</b>		
History of coronary heart disease	0.92	(0.56-1.52)
History of heart attack or angina	1.06	(0.56-2.03)

Data source: Native Hawaiian and Pacific Islander National Health Interview Survey, 2014.  
 Note: “—” denotes reference category.

†Recommended heart attack knowledge includes knowing the five major signs and symptoms of a heart attack (pain or discomfort in the jaw, neck, or back; feeling weak, lightheaded, or faint; chest pain or discomfort; pain or discomfort in the arms or shoulder; and shortness of breath) and to call 9-1-1 if a heart attack is suspected.

‡Calculated using multivariate logistic regression. Archer-Lemeshow test:  $F(7,21)=1.48; P=.23$ , indicating no evidence of lack of fit. Estimates are weighted to account for complex sampling design (sampling weights and stratification) and reflect the adult NHPI population living in the United States.

\* $P<.05$ ; \*\* $P<.01$ .

improvements in knowledge of heart attack symptoms and what to do if a heart attack is suspected at post-intervention, and each included features that may be particularly appropriate for use with NHPI persons.

The Northern California educational intervention targeted women during their visits to primary care clinics that served a large number of persons from racial and ethnic minority groups. The intervention materials were available in both English and Spanish.<sup>12</sup> Given the historical trauma shared by many NHPI communities related to American colonialism and imperialism,<sup>15</sup> NHPI persons in the US may feel more comfortable obtaining health care services in clinics that specifically target NHPI patients, such as the Native Hawaiian Health Care System (designed specifically to improve the health of Native Hawaiians residing in Hawai‘i). Additionally, the potential language barriers experienced by other Pacific Islander subpopulations may make these types of clinics more attractive to patients as they may employ community health workers and/or medical interpreters that would ensure proper translation and interpretation of materials and information into multiple languages. Thus, such clinics may provide concentrated NHPI populations to target for recommended heart attack knowledge interventions. This may be particularly important as 14% of NHPI persons

are limited in English proficiency while only 9% of the general US population is similarly limited.<sup>16</sup> Other reports, however, indicate 6.2% of NHPI persons are uninsured and that one in four NHPI persons has not used outpatient health care services in the past year.<sup>17</sup> Lack of insurance and use of clinic services by some NHPI persons would limit the reach of a clinic-based intervention.

The Georgia intervention was delivered in weekly group sessions in community senior centers. No known data is available regarding use of senior centers among NHPI persons, but the success of a heart attack knowledge intervention through group classes may be appropriate for NHPIs in other community settings. For example, churches have been shown to be effective sites for engaging NHPI communities in health-related activities and interventions.<sup>18-23</sup>

The relevant feature of the community-wide intervention trial was the use of an advisory board of leaders of community organizations and health professionals. Community advisory boards provide an opportunity for the priorities, experiences, and preferences of the persons who will be targeted by the intervention to be considered and included in the development of the intervention, and in some cases, in the implementation and evaluation of the intervention.<sup>24</sup> This type of input can help ensure the intervention is culturally appropriate and likely to be receptive to the intended participants.

The results of this study must be considered in light of limitations. The study is based on self-reported data from the NHPI-NHIS. Although there may be some concern with the quality of self-reported data, the NHIS has been conducted by the CDC and has been relied upon to monitor the health of the nation for more than 50 years. Additionally, there may be concern regarding the survey methodology to ensure the results are representative of the national population of NHPI persons. However, an assessment conducted by the National Center for Health Statistics indicated that “differences between the samples were not substantial enough to raise concerns about the underlying quality of the 2014 NHPI NHIS data” (p.2).<sup>25</sup>

## Conclusions

Our study determined that less than half of NHPI adults living in the US have the recommended level of heart attack knowledge to facilitate timely access to heart attack treatment. This is concerning given the high rates of heart-related illness and the high risk for heart attack among this population group. We believe our results contribute to the limited, but growing, literature regarding the health and health-related characteristics of NHPI persons living in the US and may inform efforts to develop educational interventions aimed at improving knowledge related to heart attack symptoms and appropriate action to take if a heart attack is suspected.

## Conflicts of Interest

None of the authors identify any conflicts of interest.

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### Authors' Affiliations:

- Fay W. Boozman College of Public Health, University of Arkansas for Medical Sciences, Little Rock, AR (HF)
- Office of Community Health and Research, University of Arkansas for Medical Sciences Northwest, Fayetteville, AR (M-RN, BR)
- College of Medicine, University of Arkansas for Medical Sciences Northwest, Fayetteville, AR (CRL, PAM)
- Division of Biostatistics, University of Tennessee Health Science Center, Memphis, TN (ZB)

### Correspondence to:

Pearl Anna McElfish PhD, MBA; 1125 North College Ave., Fayetteville, AR 72703; Ph: (479) 713-8680; Email: pamcelfish@uams.edu

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## **Formative Factors for a Statewide Tobacco Control Advocacy Infrastructure: Insights from Hawai‘i**

Lola H. Irvin MEd; Lila Johnson RN, MPH; Jessica Yamauchi MA; Joshua R. Holmes MPH; Lance K. Ching PhD, MPH; Ranjani R. Starr PhD, MPH; Catherine M. Pirkle PhD; Tetine L. Sentell PhD

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### **Abstract**

*Hawai‘i has comprehensive statewide tobacco control policies and was the first US state to raise the minimum age of sale, purchase, and possession of tobacco products to age 21 (“Tobacco 21”) in a policy including not just cigarettes, but also electronic smoking devices and other tobacco products. This insights article provides strategic thinking about tobacco control advocacy planning. Specifically, we identify formative factors critical to building and sustaining our cross-sector, statewide advocacy infrastructure that has been able to address many ongoing challenges of tobacco-use prevention and control over time. This can provide new insights for other large-scale tobacco-control advocacy efforts.*

Hawai‘i was the first US state to raise the minimum age of sale, purchase, and possession of tobacco products to age 21 (“Tobacco 21”).<sup>1</sup> As a relatively small state of 1.4 million residents and geographically remote from the mainland US, Hawai‘i has consistently passed innovative legislation to regulate and limit tobacco use across the last two decades for an estimated total savings of \$1 billion in health care costs to the state.<sup>2</sup> Hawai‘i’s Tobacco 21 policy crucially included not just cigarettes, but also electronic smoking devices and other tobacco products.<sup>3-4</sup> Hawai‘i also banned the sale of electronic smoking devices to minors (2013) and later added electronic smoking devices to all clean indoor air laws (2015).<sup>4</sup> By 2017, all four major counties had banned smoking in vehicles with children. Public school campuses from kindergarten to higher education are now smoke free.<sup>4</sup>

Hawai‘i has set ambitious policy goals that other locations have followed.<sup>5-7</sup> For instance, California followed closely with passage of its own Tobacco 21 law; three other states have since followed. Hawai‘i also initiated innovative partnerships, including collaborating with the Department of Defense, which aligned with Tobacco 21 to ban sales and possession on Hawai‘i military bases and commissaries.<sup>8</sup> Hawai‘i’s policies are consistent with both the Centers for Disease Control and Prevention (CDC)’s Best Practices for Tobacco Control Programs and the World Health Organization Framework Convention on Tobacco Control, a treaty the United States has signed but not ratified.<sup>9-10</sup>

In this Insights article, we provide strategic thinking about tobacco control advocacy planning from a small state with a strong infrastructure and large impact. Specifically, we identify the formative factors that were critical to building and sustaining our cross-sector, statewide advocacy infrastructure that has been able to address ongoing challenges of tobacco-use prevention and control over time. Factors were identified from a targeted review of relevant documents (academic, policy, media, and grey literature) and interviews with key informants (N=10), including Hawai‘i public health officials, academics, and community advocates in 2017-2018.

### **Foundational Factors**

Critical to the success of Hawai‘i’s tobacco control advocacy infrastructure were early strategic choices in building coalitions and state programs towards tobacco control supported by dedicated funding. Also important were ensuring access to cessation options and information, considering a long-term time horizon, leveraging best practice guidelines and networks, and developing robust state-wide surveillance and tobacco compliance/enforcement infrastructure. These efforts have contributed to comprehensive tobacco control policies as well as social norm change. We provide highlights from each of these foundational factors as advice to other locations considering large scale advocacy efforts.

### **Build and Sustain Coalitions**

Hawai‘i started formally building statewide tobacco control coalitions in the 1990s. These included the Interagency Council on Smoking and Health, which was formed by public and private partners (eg, American Cancer Society, American Heart Association, American Lung Association, the Hawai‘i Department of Health (DOH)) and had a specific goal of policy change. Coalition building was strongly supported by federal funds, including programmatic CDC/National Tobacco Control Program grants. A Robert Wood Johnson Foundation “Smoke-

less States” grant generated the creation of the Coalition for Tobacco-Free Hawai‘i (CTFH). This statewide entity remains active today and comprises more than 2,500 varied organizations with flexibility to include new partners. For instance, CTFH worked with environmentalist groups to pass legislation for smoke-free beaches and parks. Community Coalitions within CTFH were organized to be representative of their island populations, providing an opportunity to include and leverage diverse voices and innovations from smaller communities. Programmatic activities continue to be supported by CDC/ National Tobacco Control Program funding.

Another powerful effort that arose during the 1990s was a youth-led advocacy group called “REAL,” which was formed in the University of Hawai‘i Cancer Center to organize and promote involvement of youth around tobacco issues and was supported by the American Legacy Foundation and later by the Hawai‘i Tobacco Prevention and Control Trust Fund. This effort has evolved into the Youth Council for CTFH, which continues to be an active platform for youth engagement and advocacy for stronger tobacco regulation.

### **Dedicate Funding to Prevention and Cessation**

In 1999, the Hawai‘i state legislature passed Act 304 and created the Hawai‘i Tobacco Settlement Special Fund (TSSF) for the state’s share of the Master Settlement Agreement (MSA), which required cigarette manufacturers to pay a multi-billion settlement and set new restrictions on the sale and marketing of cigarettes.<sup>11-12</sup> Initially, the new state law, section 328L-2, Hawai‘i Revised Statutes, included distributing from the TSSF, 25% of the state’s annual MSA payments into the Hawai‘i Tobacco Prevention and Control Trust Fund.<sup>12</sup> Funding levels for the dedicated Hawai‘i Tobacco Prevention and Control Trust Fund have fluctuated over the years, and are at 12.5% of the state’s distribution of the annual MSA payment.<sup>13</sup> An important, often unseen, role of tobacco control advocates is the considerable lobbying efforts to preserve such dedicated funds.<sup>14</sup> US states typically spend little of their tobacco revenue on prevention and cessation programs, and no state currently funds tobacco prevention at the CDC-recommended level. In 2018, Hawai‘i was ranked 5th of 50 states for the amount allocated to tobacco prevention, allocating \$6.6 million, which is 48.1% of the CDC-recommended spending.<sup>9,15</sup> While substantial, this amount is small compared to tobacco industry promotional budgets.

### **Ensure Access to Prevention and Cessation Programs**

MSA-dedicated monies continue to support the Hawai‘i Tobacco Quitline, local cessation providers, and youth prevention efforts. These include a granting program for community-based cessation services specifically designed to reach subpopulations that smoke at higher rates. When new policies encourage people to quit smoking, the quitline and trained tobacco cessation specialists offer options to help individuals meet those demands. Unlike many other US states, Hawai‘i has widespread insurance coverage for its residents (92.5% of adults 18 years or older are covered)<sup>16</sup> with most plans providing some tobacco cessation

coverage; thus, options are generally available for individuals to seek this treatment.

### **Create and Support a Long-Term Vision**

The MSA allocation was guided by a formal concept-mapping process to plan for comprehensive statewide health improvements that engaged local stakeholders and national experts and was hosted by DOH.<sup>17</sup> This resulted in the Healthy Hawai‘i Initiative (HHI), funded by the TSSF, which used a social ecological approach to promoting healthy communities and focused on policy and system-level changes. HHI is now maintained within the Chronic Disease Prevention and Health Promotion Division of the DOH.<sup>18</sup>

In another example, tobacco tax reform has been successful, but was iterative, requiring sequential policies achieving slow tax increases (see Table) over many years. Currently, the Hawai‘i state cigarette excise tax is the fifth highest nationally.<sup>19</sup> Of note, Hawai‘i tobacco control efforts receive no tobacco tax revenue.

### **Use Models of Best Practices, Networks, and Expertise**

State-level work has aligned with national and international efforts, including opportunities for education/training, adoption of best practices, and networks. These are used for knowledge sharing, comparing notes, developing policy language, and strategic planning, including a shared national strategy exposing the predatory practices of the tobacco industry. Nationally and internationally gathered evidence, such as reports from US Surgeons General, are often employed as reliable, comprehensive data to support policy planning and action.

### **Support Local Surveillance Data Systems**

Local data also provide critical context. Legislators often specifically request local data and rely on it for decision-making. Hawaii’s strong tobacco surveillance has highlighted gaps, priority populations, and trends. For example, the emerging trend in 2017 that 25.5% and 15.1% of public high and middle school students, respectively, reported currently using electronic smoking devices was widely cited to provide public health rationale for decisive policy action, despite uncertain evidence around the long-term effects of these products.<sup>25</sup> Hawai‘i policy makers based their decisions on the precautionary principle to protect young people given the evidence at hand of the rapid adoption of electronic smoking devices and established risk of nicotine to young people.<sup>20</sup>

### **Change Social Norms**

In October 2017, following two other Hawai‘i counties, the Honolulu City Council unanimously approved a measure making it illegal to smoke in a vehicle with a minor present.<sup>21</sup> Opponents argued that it was “an unnecessary intrusion into people’s personal lives.”<sup>21</sup> The fact that a personal autonomy argument was not persuasive enough to receive even one “no” vote provides clear evidence of social norm change in the state. Currently, all four major counties in Hawai‘i prohibit smoking

in vehicles when children are present. As with other recent policies, these bills applied to both cigarettes and electronic smoking devices.

Decades of social norm changes have, in turn, galvanized additional legislative support that continues in a progressive direction. These efforts have created legislative champions willing to author innovative bills and comprehensive policies. The media have been supportive, accurately reporting that tobacco use is a threat to the environment and that tobacco-control policies protect Hawaii's *keiki* (children).

## Achievements and Challenges

Hawaii has achieved comprehensive statewide tobacco control and vanguard policy achievements. (See Table for key policies by focal area.) Successful policies have addressed taxes, legal age limits, involuntary smoke exposure, and environmental safety. Along with cost savings, Hawaii has seen positive health outcomes from these efforts. Smoking prevalence among public high school students dropped by 72% over two decades, from 29.2% (1997) to 8.1% (2017).<sup>2</sup> Hawaii has the third lowest adult smoking rate in the United States and is considered the second healthiest state in the nation with the longest lived population.<sup>2,22</sup> Deaths due to heart disease decreased by 34%, stroke by 44%, and lung cancer by 10%, from 2000-2002 to 2012-2014.<sup>2</sup> This is attributed, in part, to strong tobacco control and access to healthcare.

Challenges remain. Hawaii must do more to assist priority populations to avoid or overcome nicotine addiction, including Native Hawaiians and lesbian, gay, and bisexual youth.<sup>23</sup> Use of electronic smoking devices continues to rise, particularly among teens. New nicotine delivery systems are constantly emerging and electronic smoking devices remain unregulated in the state (eg, no license or permit required, no product tax, and on-line sales widespread). An electronic smoking device tax has been debated by the legislature for several years without successful passage.

The 2018 legislative session highlights continued challenges and the importance of remaining vigilant to tobacco industry tactics. Many case studies have shown that the tobacco industry lobbies regularly against increases in tobacco tax, but even advocates in Hawaii were surprised by the outcome of the 2018 session that resulted in a bill that preempted counties from having or passing tobacco sales legislation.<sup>24-26</sup> Attempts to legally ban the internet sales and shipping and handling of electronic smoking devices except to retailers and distributors was also overturned. The Hawaii Youth Tobacco Survey indicates friends are the leading sales source for these products.<sup>27</sup> With passage of Tobacco 21 and the changing tobacco landscape, there is a need to rethink enforcement protocols and sampling methodology for compliance/enforcement to ensure compliance of retailers selling not just combustible products but also electronic cigarettes, the liquid mixtures that are used in electronic cigarettes (sometimes called e-juice), and other emerging products.

## Considerations

Hawaii has unique contextual factors that may impact the relevance of these lessons for other communities. Hawaii is a consumer protection-oriented and health conscious state. With a consistently one-party government, Hawaii legislators can often focus less on partisan politics and more on data-driven policy. Hawaii is also a small state with ready access to policymakers. This builds long-term relationships, nontraditional partnerships, even friendships, fostering engagement and willingness to collaborate and sometimes compromise to achieve important tobacco control policy goals.

## Conclusions

While disproportionately out-funded, the enduring commitment of the cross-sectorial network, and deliberately-established shared goals, has allowed Hawaii to be responsive to the tobacco industry's evolving products and marketing strategies. Hawaii has many successes built upon decades of coalition building towards comprehensive tobacco control. Continuing restrictions have shifted social norms and broadened the assumed purview of government in restricting tobacco and have also allowed for a number of innovative policy successes, but have not precluded all challenges. The control of electronic smoking devices in particular demands strong advocacy and knowledge-sharing within and across communities, states, and nations given the pace of technological developments, the appeal of the numerous varieties of flavored e-liquids, and shifting nomenclature (from e-cigarettes to electronic smoking devices to vaping products).<sup>3</sup>

Comprehensive statewide tobacco control programs and larger financial investment in comprehensive tobacco control programs are well known to be effective.<sup>9,28</sup> This work provides new insights into how to build and sustain effective, cross-sector programs that are critical to addressing emerging issues and maintaining existing gains.<sup>28-29</sup> Observations from Hawaii also corroborate recent research around factors in successful smoke-free policies in the European Union, including engaging across different types of organizations, the importance of personal interaction, long-term collaboration and trust, and the need for information sharing across varied levels of governance.<sup>29</sup> Findings from this small state can inform and inspire advocacy efforts elsewhere.

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### Authors' Affiliations:

- Hawaii State Department of Health, Honolulu, HI (LHI, LJ, JRH)
- Hawaii Public Health Institute, Honolulu, HI (JY)
- Hawaii State Department of Human Services, Honolulu, HI (RRS)
- Office of Public Health, University of Hawaii at Manoa, Honolulu, HI (CMP, TLS)



Table 1. Key Tobacco Control Policies by Focal Domain in Hawai'i			
Focal Area	Date	Policy	Level of Passage (state, county)
Restricting Access	1987	Raised the legal age to buy tobacco products from 15 to 18 years	state
	2013	Eliminated self-service displays for all tobacco products.	state
	2014	Hawai'i County prohibits the sale of tobacco products to anyone under the age of 21 years	county
	2015	Prohibit the consumption, possession, and sale of tobacco products to persons under the age of 21 years.	state
Fines	1998	Fines and penalties increased for the illegal sale of tobacco products to minors. The fine was set at a minimum of \$500 for the first offense, and up to \$2000 for subsequent offenses.	state
	2005	All tobacco retailers in Hawai'i are required to obtain a retail tobacco permit issued by the Department of Taxation. This also provided that permit holders are subject to inspection, investigation, and penalties by the Department of the Attorney General	state
Smoke Free/Environmental Controls	1993	Smoking became prohibited in licensed childcare facilities during hours of operation	state
	1993	"Tobacco-Free School System Policy" which prohibits smoking by any person on all campuses, at school-sponsored activities, in school vehicles, and administrative offices.	state
	1999	Building off of previous county efforts, a statewide policy passed prohibiting the distribution of sample tobacco products on or in any public street, sidewalk, or park, or within 1000 feet of any school attended by minors. Additionally, it prohibits the distribution of tobacco promotional materials within 1,000 feet of any school attended by minors.	state
	2002	Maui, Kaua'i, and Honolulu Counties prohibit smoking in restaurants and some bars	county
	2003	Hawai'i County prohibits smoking in any restaurant	county
	2004	Prohibited smoking at any public school function.	state
	2006	Hawai'i's Clean Indoor Air Act, also known as the "Smoke-Free Workplaces Law," passed in 2006 and prohibited smoking in enclosed and partly enclosed areas statewide, expanding on county efforts.	state
	2008	Hawai'i County bans smoking at all County beaches, parks, and recreational facilities	county
	2010	Hawai'i County bans smoking in any vehicle with children less than 18 years of age	county
	2012	Honolulu County bans smoking at City and County parks and beaches, and bus stops	county
	2013	Banned the sale of electronic smoking devices to minors (18 years at the time)	state
	2014	Banned smoking at any state public housing project or state low income housing project	state
	2014	Maui County bans smoking at county beaches, parks, and recreational facilities	county
	2015	Made state parks and beaches smoke-free	state
	2015	Added e-cigarettes to all smoking prohibitions	state
	2017	Kaua'i County prohibits smoking in vehicles with children under 13 years of age	county
2017	Honolulu County prohibits smoking in vehicles with children under 18 years of age	county	
2018	Maui County prohibits smoking in vehicles with children under 18 years of age	county	
Cigarette Taxes	2002	Changed from \$1.00 to \$1.20 (for a pack of 20)	state
	2003	Changed from \$1.20 to \$1.30	state
	2004	Changed from \$1.30 to \$1.40	state
	2006	Changed from \$1.40 to \$1.60	state
	2007	Changed from \$1.60 to \$1.80	state
	2008	Changed from \$1.80 to \$2.00	state
	2009	Changed from \$2.00 to \$2.60	state
	2010	Changed from \$2.60 to \$3.00	state
2011	Changed from \$3.00 to \$3.20	state	

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## Perspectives on the Epidemiology of Gout and Hyperuricemia

Youssef M. Roman PharmD, PhD

*HJMPH contributing editor of the Daniel K. Inouye College of Pharmacy (DKICP) Scripts column is Jarred Prudencio PharmD, BCACP, BC-ADM. Dr. Prudencio is currently Assistant Professor of Pharmacy Practice, and is a Board Certified Ambulatory Care Pharmacy Specialist with experience in outpatient family medicine and specialty clinics.*

### Abstract

Gout is the most common inflammatory arthritic condition affecting more men than women. Hyperuricemia and the deposition of urate crystals into the joints are the hallmarks of gout. The prevalence of gout and hyperuricemia is rising in the United States and world-wide possibly due to the aging population, comorbidities, and other lifestyle factors. Gout and serum uric acid (SUA) levels are highly heritable, underscoring the role of genetics on disease risk and possibly the racial disparities in gout prevalence. However, high consumption of high fructose corn syrup, alcohol, select dietary lifestyles, and use of diuretics are associated with higher SUA levels and increased risk for developing gout. Adopting healthy diet and lifestyle modifications can lower SUA levels. Nonetheless, diet-based approaches for the management of gout should remain a secondary approach to urate lowering therapy.

### Epidemiology of Gout and Hyperuricemia

Gout is the most common inflammatory arthritic condition characterized by the deposition of urate crystals into the joints.<sup>1</sup> Data from major US healthcare systems and the National Health and Nutrition Examination Survey (NHANES) have shown a rise in prevalence of gout and hyperuricemia (Figure 1).<sup>2,3</sup> In the United States, the prevalence of gout has significantly increased from 2.9% in NHANES III 1988-1994 to 3.9% in NHANES 2007-2008.<sup>2</sup> The worldwide prevalence and incidence of gout are also rising. For instance, the South Korean National Health claims indicated that the prevalence increased from 0.35% in 2007 to 0.75% in 2015, and the incidence rate significantly increased from 1.5 in 2007 to 1.9 in 2015 per 1000 per year.<sup>4</sup> Conversely, the prevalence of gout remains unchanged in some countries. A study in Taiwan reported that the prevalence of gout remained relatively unchanged from 6.4% in 2005 to 6.2% in 2010.<sup>5</sup>

The prevalence of gout substantially differs across geographical regions of the world. While Greece presents with the highest prevalence in Europe (4.75%), other countries like the Philippines, Jamaica, Iran, South Korea, and select African countries have reported prevalence of less than 1%.<sup>4,6</sup> This geographical differential in prevalence further supports the role of environment, dietary habits, and other lifestyle behaviors that modulate the risk for developing gout.<sup>7</sup>

In the United States, the prevalence of hyperuricemia has significantly increased from 19.1% in NHANES 1988-1994

to 21.5% in NHANES 2007-2008.<sup>2</sup> Although the prevalence of gout is markedly different between men (6%) and women (2%), the prevalence of hyperuricemia is similar between men (21.2%) and women (21.6%).<sup>2</sup> This considers the gender difference in the case definition of hyperuricemia (SUA >5.7 mg/dL for women vs >6.8 mg/dL for men). According to the NHANES 2007-2008, the mean serum uric acid (SUA) level was 6.14mg/dL among men and 4.87mg/dL among women.

The different thresholds for classifying hyperuricemia and prevalence of gout between men and women have a variety of sources such as amount of alcohol consumption and muscle mass.<sup>8</sup> In addition, circulating estrogen levels significantly affects the risk of hyperuricemia and gout between sexes due to its uricosuric effect.<sup>9,10</sup> However, this protective effect decreases as women reach the postmenopausal age when circulating estrogen levels decline. Additionally, as age increases the risks of developing hyperuricemia and gout also increase due to declining kidney function, risk of dehydration, and polypharmacy due to the multiple comorbidities.<sup>3</sup> Thus, the combination of decreased estrogen levels and complications of aging-related comorbidities suggest that women might be at a higher risk for developing gout at later stages in life than men.

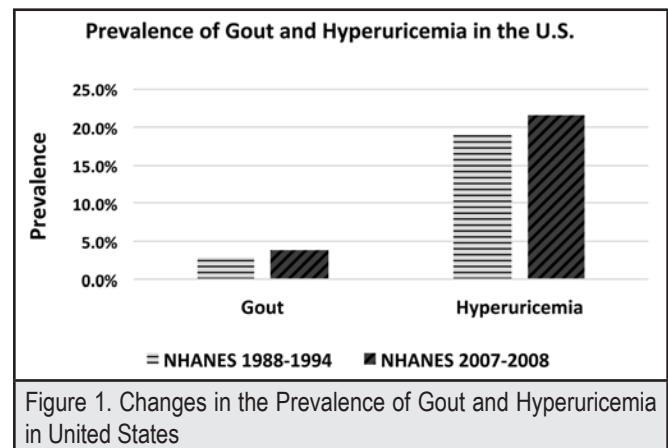


Figure 1. Changes in the Prevalence of Gout and Hyperuricemia in United States

There are multiple limitations associated with the methods used to assess the prevalence or incidence of gout such as relying on participants' self-report, recall bias, sampling limitations, misdiagnosis or case-definition of gout, and the timing of conducting the study. Therefore, the need for replication and longitudinal studies are warranted to accurately quantify the prevalence and incidence of gout, which is a debilitating and costly disease to its sufferers and society at large.<sup>11</sup>

### Hyperuricemia and Gout in Hawai'i

Epidemiological studies have found disparities in the ethno-cultural and geographical distribution of hyperuricemia and gout in the Asian-Pacific regions.<sup>12,13</sup> These findings have led investigators to postulate that indigenous groups throughout the Oceania regions may be predisposed to hyperuricemia and gout. The state of Hawai'i has the largest Native Hawaiian and Other Pacific Islander (NHOPI) populations in the United States.<sup>14</sup> The prevalence of hyperuricemia and gout in NHOPI living in Hawai'i is a knowledge gap.<sup>12</sup> Without data on the distribution of hyperuricemia and gout burden, it is not possible to directly ascertain the impact of both conditions in Hawai'i, reduce their prevalence, and mitigate their consequences, such as diabetes and chronic kidney disease (CKD).<sup>12,15,16</sup> Moreover, individuals of Pacific Islander descent living in Hawai'i are at an increased risk for developing hyperuricemia and gout, partly due to possible genetic predisposition and historical change in dietary lifestyles.<sup>12</sup>

While there is an expectation of a high prevalence of hyperuricemia and gout in Hawai'i, there is no comprehensive assessment of this prevalence reported in the literature.<sup>12</sup> Additionally, the hyperuricemia and gout prevalence reports from Hawai'i are either significantly outdated or lacking for select ethno-racial groups such as the NHOPI.<sup>17</sup> The absence of this data is a prime example of health disparity of knowledge in these unique populations and missed opportunities to address their high risk for developing CKD and other gout-related comorbidities.

### Pathogenesis of Hyperuricemia and Gout

Purines are converted to hypoxanthine, xanthine, and ultimately uric acid (UA) via the xanthine oxidase enzyme. Based on an average purine content diet, 800-1000mg of UA is produced daily.<sup>18</sup> Of this amount, 500-600mg is produced endogenously while the remaining 200-300mg is produced from dietary sources of purines.<sup>18</sup> Of the amount produced daily, approximately 70% is excreted by the kidney while the remainder is eliminated via the gastrointestinal tract, where it is degraded by bacterial uricase (Figure 2).<sup>1</sup>

While kidney function is critical in UA disposition, the role of uricase-producing bacteria in the intestine raises the question of whether changes in gut microbiome influences the risk of developing gout. A small study of gout patients compared to those with type 2 diabetes and metabolic syndrome identified that the intestinal microbiota profiles are distinct in both the organismal and functional structures. Furthermore, the reference

microbial gene catalogue for gout cases revealed disorders associated with purine metabolism and butyric acid biosynthesis, both of which to be the basis for developing gout.<sup>19</sup>

The level of SUA is the net effect of dietary intake of purine sources, endogenous cell turnover, and UA excretion. The imbalance between UA production and excretion is the hallmark of hyperuricemia and progenitor for monosodium urate crystal formation. Defective renal elimination of UA, known as UA underexcretors, accounts for 80%-90% of gout cases. However, inherited genetic disorders such as Lysch Nyhan Syndrome, Tumor Lysis Syndrome, or high intake of purine sources can result in UA overproduction, which accounts for 10% of gout subtypes.<sup>1,18,20,21</sup>

UA is extensively (~90%) reabsorbed from the kidney via the Four Compartment Theory, which allows a small fraction of UA to be excreted (Figure 3).<sup>22</sup> Though SUA levels are inversely associated with kidney function, higher baseline SUA levels can naturally exist in normal kidney function. The etiology of such discordance between kidney function and SUA levels in some individuals has been attributed to genetic variants within select UA transporters, mainly ABCG2, NPT1, and URAT1, which can significantly modulate SUA levels.<sup>23</sup> These genetic variants can render some individuals to be more efficient at reabsorbing UA while making others less efficient at excreting UA (Figure 2).

### Genetics of Hyperuricemia and Gout

Hyperuricemia and gout are highly heritable with estimates of up to 45% and 65%, respectively.<sup>24</sup> The recent advances in genetic tools applied to large populations, such as genome-wide association studies (GWAS), have helped to elucidate major genetic variants in the UA disposition pathway which may predict hyperuricemia or gout. The genes that have been repeatedly identified to be associated with SUA levels mainly involve transporter-encoding genes affecting UA excretion such as *ABCG2* and *SLC17A1*, UA reabsorption genes such as *SLC2A9*, *SLC22A11* and *SLC22A12*, the lipid-metabolizing gene *GCKR*, and the scaffolding gene *PDZK1*.<sup>25</sup>

The prevalence of hyperuricemia and gout varies with race and ethnicity.<sup>26</sup> For example, African-Americans and Hmong tend to have a higher prevalence of gout compared to Caucasians and Europeans.<sup>2,26,27</sup> This difference in racial prevalence parallels the prevalence of genetic variants, primarily the single nucleotide polymorphisms consistent with those identified by GWAS.<sup>23,28-30</sup> These genetic findings may play a role in the explanation for why some populations have higher documented prevalence of gout.<sup>6,31</sup>

Although these genetic variants are found to be differentially prevalent across racial groups, at least one group studying several populations found that the magnitude and direction of impact these genetic variants were consistent across most of the studied populations.<sup>29</sup> The etiology of gout is a heterogeneous process involving genetic and non-genetic factors. While key genetic variants associated with gout have been identified, recent candidate genes studies and GWAS in Japanese patients with

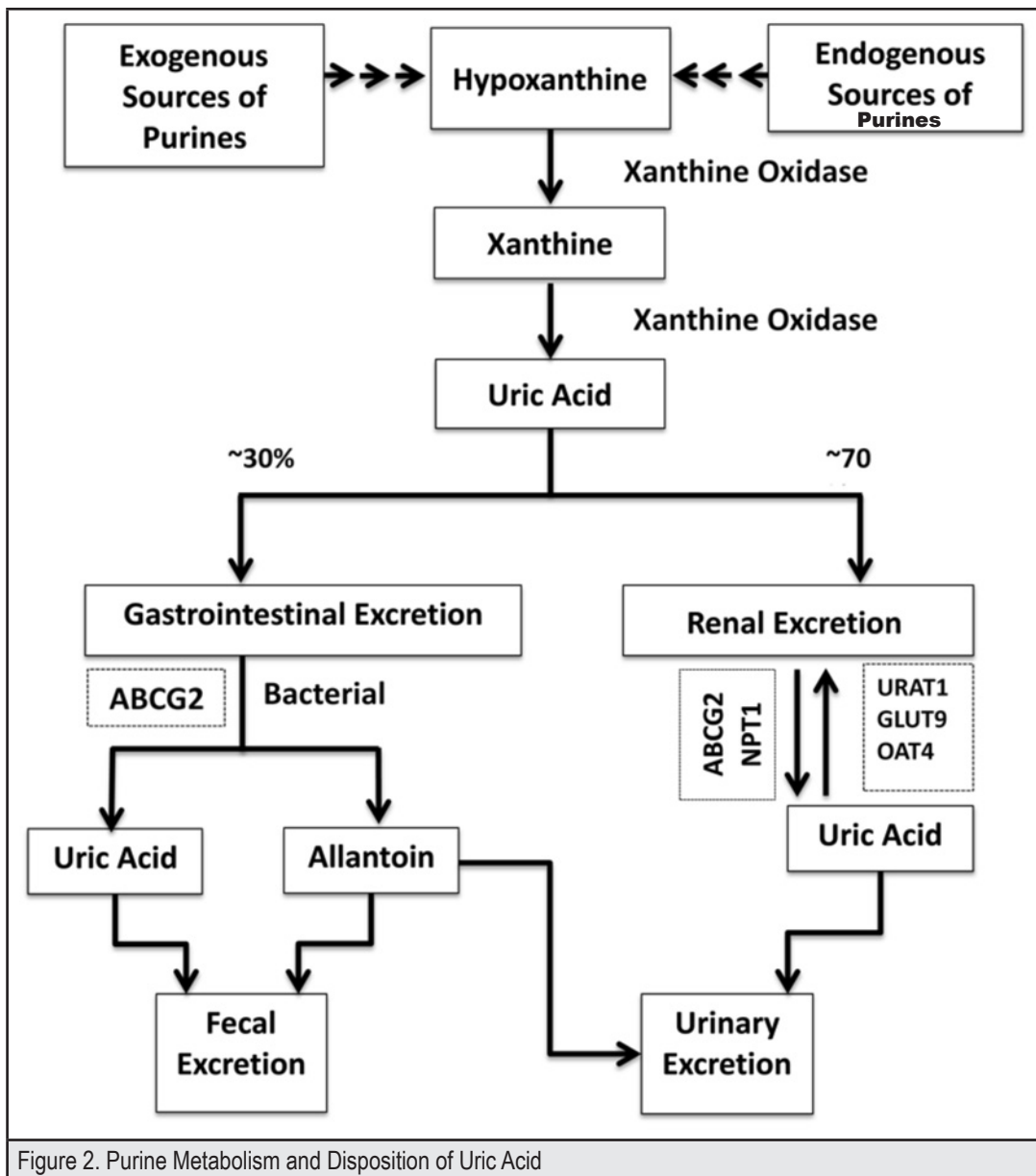


Figure 2. Purine Metabolism and Disposition of Uric Acid

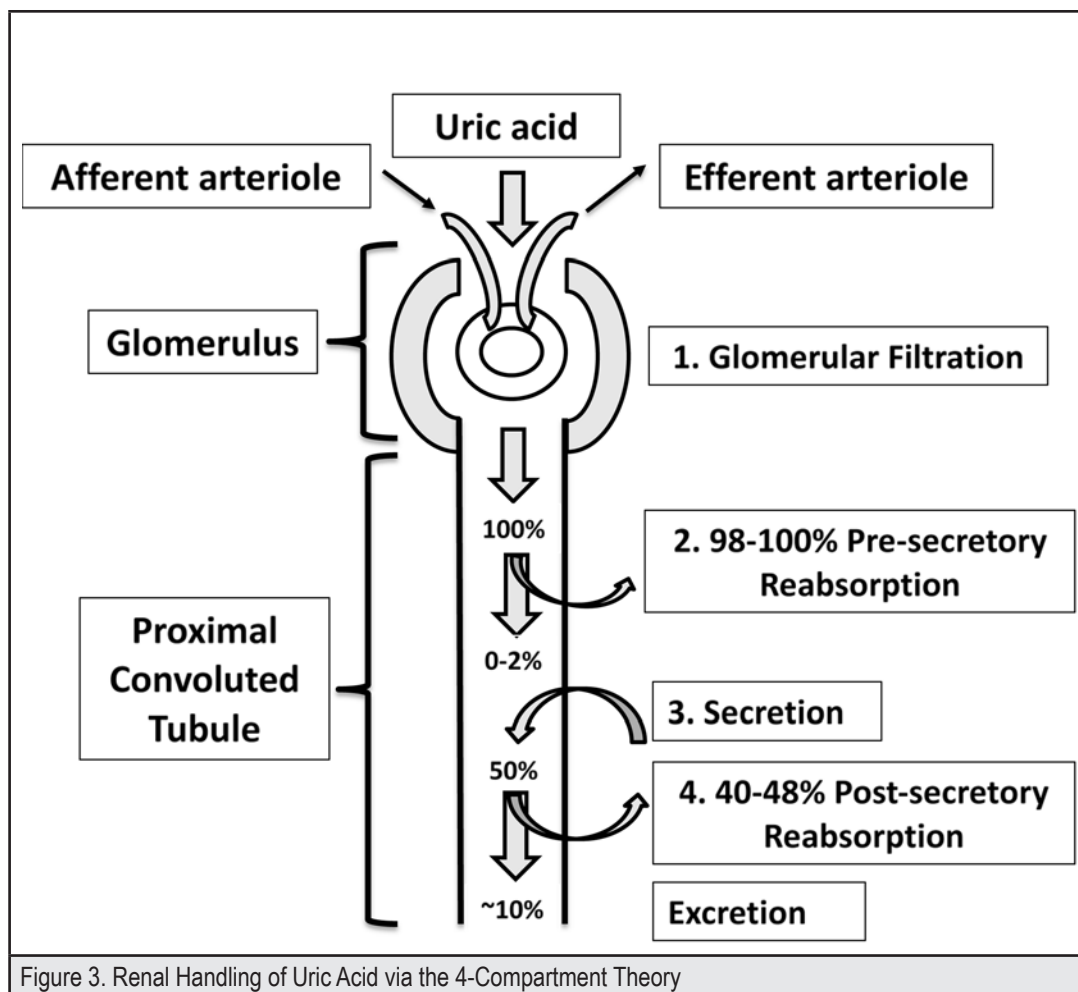


Figure 3. Renal Handling of Uric Acid via the 4-Compartment Theory

gout have suggested some genetic variants are associated with the gout subtypes overproduction, underexcretion, or combined.<sup>32</sup> Specifically, genetic variants were found in *SLC16A9* and *SLC22A11*, which may predict the overproduction and underexcretion of UA phenotype, respectively.<sup>33,34</sup> Comparably, genetic polymorphisms within the efflux *ABCG2* transporter were found to influence the response to urate lowering therapy, mainly allopurinol.<sup>35,36</sup>

### Hyperuricemia and Gout Risk Factors

Though age is a key predictor of developing gout, male sex is associated with higher incidence of gout than females (3:1).<sup>3</sup> However, postmenopausal women have a similar or increased risk for developing gout compared to men due to declining estrogen levels. In men, testosterone replacement therapy is associated with elevated SUA levels and increased blood pressure through the activation of the renin-angiotensin system (RAAS).<sup>37,38</sup> This observation is consistent with the potential effect of hyperuricemia on the development of hypertension through the activation of RAAS.<sup>39</sup> Comorbidities, use of select drugs, and sex hormone levels all modulate SUA and thus the risk of gout. Specifically, the changes in androgen levels in

aging men and circulating estrogen in postmenopausal women underscore the comparable risk of developing gout in both elderly men and women.

### Diuretics Use and Gout

Diuretics are also associated with elevated SUA and significantly increase the risk of worsening gout symptoms and new onset of gout flares.<sup>40</sup> An analysis of a large population-based cohort identified that the use of thiazide or loop diuretics was significantly associated with new incidence of gout compared to no use of diuretics (HR 1.48 [95%CI, 1.11 to 1.98]). Although not significantly different, the loop diuretics had a higher risk (HR 2.31 [95% CI, 1.36 to 3.91]) than thiazide diuretics (HR 1.44 [95% CI, 1.00 to 2.10]) with incident gout.<sup>41</sup>

### Effect of Select Diet on Uric Acid and Gout High Fructose Corn Syrup

It is well documented that higher intake of purine sources, especially red meat and seafood, can worsen existing gout symptoms or increase risk of developing gout. Higher intake of high fructose corn syrup sources in products such as soft drinks can also result in new onset of acute gout attacks.<sup>42,43</sup> The con-

sumption of high fructose corn syrup has dramatically increased over the past few decades which has been cited as a contributing factor for the increase in the prevalence of hyperuricemia and gout in countries where fructose is commercially used as a sweetener.<sup>44</sup> The mechanism by which fructose increases SUA is not clearly understood, but it has been proposed that fructose gets reabsorbed from the kidney and further metabolized to fructose 1-phosphate in the liver.<sup>45</sup> This conversion results in a sharp depletion of ATP subsequently increasing UA levels. The depletion of ATP further stimulates the synthesis of purine nucleotides causing more UA production.<sup>42</sup> In addition, a substantial amount of ingested fructose is converted into lactate, which competes with UA for excretion causing an increase in SUA levels.<sup>46-48</sup> Collectively, these are the mechanisms by which consumption of high fructose corn syrup can increase the risk of developing gout or gout attacks.<sup>43</sup>

### **Alcohol**

Select forms of alcohol have also been implicated in the development of gout or gout attacks, mainly due to the varying levels of purine contents. Specifically, beer tends to have the greatest effect on UA due to high purine contents and high percent of alcohol, while wine shows the lowest risk.<sup>8,49</sup> The effect of alcohol on UA production results from the conversion of ethanol into Acetyl-CoA, which leads to degradation of purine trinucleotides which increases levels of UA precursors. Like fructose, the formation of lactic acid from ethanol metabolism further leads to higher SUA.

### **Diet and Urine pH**

UA is a weak acid with a pKa of 5.8 and predominantly found in the ionized form, urate. Since urine pH is critical for determining the amount of UA that is reabsorbed from the proximal convoluted tubule (PCT), we can postulate that chronic exposure to pH modifiers have a substantive effect on the amount of ionized form of urate in the PCT.<sup>50</sup> Thus, sources that acidify the urine may enhance the UA reabsorption, causing the buildup of UA in the kidney and resulting in an acute UA nephropathy and possible UA kidney stones.<sup>7,51</sup> On the contrary, diets rich in reduced fat such as skimmed milk have been shown to decrease UA absorption.<sup>7</sup>

### **Diet and Gout Triggers**

Flynn, et al, surveyed the frequency of select dietary gout attack triggers in 2051 New Zealander patients with gout.<sup>52</sup> The study identified that 71% of the study participants self-reported one or more dietary triggers of gout attack. The most commonly reported triggers were seafood (63%), alcohol (47%), red meat

(35%), and tomatoes (20%).<sup>52</sup> While the effect of seafood, alcohol and red meat on the risk of gout is well documented, the role of tomatoes in gout attacks is startling. Although the study did not demonstrate the effect of tomato consumptions on acute gout attacks, it explored the physiological basis for this observation by associating the weekly consumption of tomatoes and SUA levels. In fact, retrospective analyses of major longitudinal cohorts such as the Cardiovascular Health Study and the Framingham Heart Study showed a significant increase in SUA levels of 0.7  $\mu\text{mo/L}$  (0.012 mg/dL) with one serving per week in tomato consumption.<sup>52</sup> On one hand, the study corroborates that the avoidance of tomato consumption in patients with gout is not unfounded practice. On the other hand, a prospective clinical trial in 35 young women showed that pre-meal tomato intake has been significantly associated with a decrease in SUA with 0.16 mg/dL.<sup>53</sup> This difference in outcomes can be attributed to the method of tomato preparation, which can influence the contents of chemicals that can affect urate levels.

### **Diet Prescription for Gout**

Weight loss, physical exercise, vitamin C supplementation, soy-containing products, low-fat milk, DASH diet, and consumption of coffee and cherries have been linked to lowering SUA and reduced incidence of acute gout attacks.<sup>7,54-58</sup> Counseling patients on the importance of dietary and lifestyle modifications and avoidance of gout attack triggers can garner additional benefits for optimal management of gout. However, given the current evidence, the excessive focus on the dietary aspect of gout management may adversely and negatively affect the adherence to the urate-lowering therapy in patients with gout. Thus, dietary intervention should be a secondary approach to urate-lowering therapy to manage patients with gout while reinforcing gout pharmacotherapy as the focal point in gout management.

### **Conclusions and Clinical Implications**

The rise in prevalence of gout could be related to trends such as aging, comorbidities, polypharmacy, and select lifestyle factors. Gout is associated with reduced quality of life and high care cost. The development of gout and hyperuricemia is a heterogeneous process that involves multiples factors including genetics, drugs, and diet. These factors can be exploited as tools to assess the patient's risk for developing hyperuricemia and gout as well as opportunities to mitigate the risk of gout attacks and drug selection.

Author's Affiliation:  
Daniel K. Inouye College of Pharmacy, University of Hawai'i at Hilo, Hilo, HI

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# HAWAI'I JOURNAL WATCH

KAREN ROWAN MS

**Highlights of recent research from the University of Hawai'i and the Hawai'i State Department of Health**

## PREVENTING CALCIFICATION IN THE BODY

Calcification of soft tissues occurs in diseases such as atherosclerosis, diabetes, and kidney failure. New findings from proof-of-concept studies show a molecular mechanism that regulates calcification. Senior author Olivier Le Saux PhD, with the John A. Burns School of Medicine, and colleagues investigated a transmembrane protein called ABCC6, which transports ATP out of cells where it is converted to pyrophosphate, a major calcification inhibitor. They found that supplementing ABCC6-deficient mice with pyrophosphate via injections, drinking water, or food effectively prevented calcification. This could point to ways to avert abnormal calcification occurring in human disorders. The findings were published in several scientific journals (<https://bit.ly/2H23aC4>, <https://bit.ly/2rGhgP2>, <https://bit.ly/2QynUkE>).

## HOW HUMOR HELPS FOSTER FAMILIES

Many foster parents discontinue fostering within one year, but a new study finds that humor can be used as a protective factor to addressing the challenges of fostering. Francie Julien-Chinn PhD, with the Myron B. Thompson School of Social Work, co-authored a study that included interviewing 20 foster families in one state who had been licensed for at least five years and were rated as having healthy family functioning on a standardized assessment. Results indicated that the families used humor to find relief in difficult circumstances and to maintain their authority when they felt challenged. Understanding how foster parents use humor can help case workers to better serve foster families, the researchers concluded in their study (<https://bit.ly/2EDAJse>), published in the *Journal of Public Child Welfare*.

## SUICIDE PREVENTION EFFORTS FOR NATIVE HAWAIIAN YOUTH

Native Hawaiian teens and young adults are at increased risk of dying from suicide. To better reach these youth, suicide prevention efforts must be culturally guided, according to a paper from lead author Deborah Goebert, DrPH, with the John A. Burns School of Medicine and UH Public Health. For example, Native Hawaiian sayings can be used to frame a program. Youth can be taught cultural values to help them resolve conflicts such as Ho'ohuli, which means to curl like a breaking wave and shift one's thinking, or Ho'ololi, which means to transform one's thoughts or behaviors. The concepts of community and relationship to the environment can be applied to teaching coping skills. Broad cultural integration can help individuals develop the tools to become healthy and resilient, according to the paper (<https://bit.ly/2S9tZWj>), published in *Psychological Services*.

## IMPROVING MAMMOGRAMS

A promising approach to reducing the number of women who undergo a breast biopsy after a mammogram, but then turn out not to have breast cancer, is to utilize computer diagnostics to refine mammogram results. In a new study, researchers including senior author John Shepherd PhD, of the UH Cancer Center, conducted high-level mammograms on 109 US women. They found that using radiomics, which means analyzing a mass by extracting a large number of image features from the mammogram data, along with three-compartment breast imaging, which means conducting a pixel-by-pixel analysis to estimate the water, lipid, and protein content of each pixel, would lead to fewer unnecessary biopsies. However, the techniques need further refinement, as they may also erroneously eliminate needed biopsies, the researchers said in their paper (<https://bit.ly/2rBYKre>), published in *Radiology*.

## SALMONELLA IN HAWAI'I WASTEWATER

Researchers including Pamela O'Brien, of the Hawai'i State Department of Health, analyzed water samples that had previously been collected from the Sand Island Wastewater Treatment Plant over the course of a year. A technique called pulsed-field gel electrophoresis was used to compare the samples to biological samples that had been collected at health clinics on O'ahu during the same period. Nine strains, including one outbreak-associated strain and numerous clinically rare strains, were concurrently detected in the samples from the clinics and the samples of wastewater. This supports the feasibility of using wastewater in surveillance for disease, the researchers wrote in their paper (<https://bit.ly/2PMSF4D>) published in the journal *Environmental Science and Technology*.

## COMPLEMENTARY AND ALTERNATIVE MEDICINE USE AMONG FILIPINOS IN THE UNITED STATES

Among Filipino adults in the United States, the most commonly used complementary and alternative medicine (CAM) therapy is taking multivitamin supplements, with 66% percent reporting ever using these supplements, according to a recent paper from researchers led by Rhea Faye Felicilda-Reynaldo EdD, RN, of the School of Nursing and Dental Medicine. The researchers analyzed data from the 2012 National Health Interview Survey to explore the patterns of CAM use of US Filipinos. Results also showed that 22% ever used herbal/nonvitamin supplements, and 16% used chiropractic manipulation. The top reasons given for using CAM therapies were that they are natural (16.3%) and have a mind-body approach (14.7%). More research is needed on this population's high use of supplements, according to the paper (<https://bit.ly/2S7icYh>) published in the *Asian/Pacific Island Nursing Journal*.

# THE WEATHERVANE

RUSSELL T. STODD MD; CONTRIBUTING EDITOR

**TAKE HEART, AMERICA. SOME GOOD THINGS ARE HAPPENING.** A bit frightening to note we have passed the 50th anniversary of the Surgeon General's report on smoking and health, a powerful document that brought tobacco to the public's attention. The discovery that tobacco causes cancer didn't happen in a lab or spring from clinical trials. It came from careful analysis of mounds of data. Your editor was in medical practice at that time, and was proud of the AMA stand. It is now half a century that we have been preaching to our tobacco smoking patients that nicotine addiction is a fatal disease. Many do not want to believe, of course, but the statistics prove the point. According to new data published by the Centers for Disease Control and Prevention (CDC) an estimated 14% of adults admitted in 2017 to every day tobacco use. In 1965 that number was 43%, and a drop of this magnitude represents a profound decline in tobacco use. This is a remarkable public health accomplishment which demonstrates that current strategies are working and need to be pursued. Yet, each day 3,200 youth (younger than 18) try their first cigarette and 2,100 progress to become daily smokers. The battle continues.

## **THE JOINT COMMISSION: MUCH ADO ABOUT NOT MUCH AT ALL.**

Research recently published in the British Medical Journal (BMJ) punched holes in the claims of federally approved organizations about benefits of the hospital accrediting industry. The data revealed that patients who select a hospital accredited by the Joint Commission get no better results over hospitals reviewed by other accrediting organizations. This follows a report last year in the Wall Street Journal that problem-plagued facilities routinely kept their joint Commission endorsement. These reports come amid mounting federal oversight of the accreditation system. The Harvard University study challenges the assertion that patients benefit when a hospital is accredited. Big wealthy hospitals that generally have more resources are more likely to be Joint Commission accredited, and the thinking is they have better outcomes. Ashish Jha, director of the Harvard Global Health Institute, an author of the study said, "What you find is that it doesn't have a big effect, and it really makes you worry. We've put a lot of faith and resources into accreditation." Like others Dr. Jha has been a critic of the process. So, it seems that the accreditation industry has produced a lot of wheel-spinning without much benefit. And that's where a big medical budget item needs to be examined.

## **ROLL THE DRUMS. SOUND THE HORNS.**

You won't hear about it, but the Trump administration has saved Americans \$26 billion on prescription drugs. Yes, over the first 20 months since he was elected, an astounding 1,617 generic drugs identical to branded versions have become available. They are sold at much lower prices when the patents expire. The Council of Economic Advisers measured the savings at \$26 billion. Most amazing is that the Food and Drug Administration (FDA) is speeding up even as fewer patents expire. Commissioner Scott Gottlieb is clearing out an application backlog. For all the hoopla about European health care systems, the American generics system is the envy of the world. Nine in ten

prescriptions in the United States are cheaper generics saving \$265 billion last year, compared with 70% in Canada and less than 50% in Europe. The FDA notes that as of August 2018 the relative price of prescription drugs was lower than December 2016, which is a dose of reality to anecdotes about skyrocketing costs. The curious part is that our windy chief executive hasn't taken credit for the good news.

## **THIS SHOULD NOT BE HAPPENING.**

Data recently released from CDC show that life expectancy for Americans fell again last year pushed down by the sharpest annual increase in suicides in almost a decade. The United States lost three tenths of a year in life expectancy since 2014, reversing what is expected in a developed nation, and lagging far behind other wealthy nations. As drug and suicide mortality has risen, deaths from heart disease, the nation's leading killer went down slightly, but failed to offset mortality from other causes. Life expectancy in Japan is 84.1 and 83.7 in Switzerland, first and second in the most recent ranking by the Organization for Economic Cooperation and Development. The United States is 29th at 78.6 years. Drug overdose deaths skyrocketed between 2015 and 2017 for adults between ages 25 and 44. The main culprit was fentanyl and other synthetic opioids that became pervasive in illicit drugs in the United States around that time.

## **SOMETIMES YOU NEED TO HAVE A VENOMOUS FRIEND.**

In Havana, Cuba, Pepe Casanas, 78, has discovered a tried and true way to treat his rheumatic pain. Once a month for the past 10 years, Casanas seeks out a blue scorpion, which is endemic to Cuba, and lets it sting him. "I put the scorpion where I feel the pain," Casanas told Reuters. After the sting it hurts for a while, "then it calms and goes away and I don't have any more pain." In fact researchers have confirmed that the scorpion venom has anti-inflammatory and pain relief effects. It may even delay cancer growth in some patients. A Cuban pharmaceutical company has been selling a homeopathic pain remedy called Vidatox made from scorpion venom. Casanas a former tobacco farmer takes a simpler route. He sometimes keeps a scorpion under his straw hat for luck where he says it likes the shade and humidity.

## **ADDENDA**

- George Washington used household chalk as a tooth whitener.
- Coca Cola spends more money on containers than it does on making the soda.
- Knee high to a grasshopper: The knee-high measurement of an average-sized grasshopper is about ½ inch.
- I started a grease fire at McDonalds. Threw a lighted match into the cook's hair.
- We may come to realize that chastity is no more a virtue than malnutrition.
- Advertisements contain the only truth to be relied on in the newspaper.

## **ALOHA AND KEEP THE FAITH rts**

*(Editorial comment is strictly that of the writer.)*

# Mahalo Peer Reviewers!

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