

Cancer in the US Associated Pacific Islands (UASPI): history and participatory development

Abstract: The US-associated Pacific Island jurisdictions (USAPI) have great disparities in health care and comprehensive cancer care compared to the United States. Cancer mortality ranks first or second among the leading causes of death in most of these island nations. The USAPI has formed the Cancer Council of the Pacific Islands (CCPI), an indigenous council to identify and address the cancer health disparities of the region. The CCPI efforts were formally launched in 2002 with the support of the Center to Reduce Cancer Health Disparities, a Center of the National Cancer Institute (CRCHD-NCI) and the National Center for Minority Health Disparities, a Center of the National Institutes of Health (NCMHD-NIH). Facilitating partners are the Department of Family Medicine and Community Health, University of Hawai'i and 'Imi Hale - Native Hawaiian Cancer Network, a program of Papa Ola Lōkahi. The objectives of this initiative are to describe and address the cancer health disparities in the USAPI. Over the past 2 years there has been considerable progress in identifying and prioritizing cancer prevention and control needs; launching cancer prevention and control efforts in each of the jurisdictions; and leveraging additional funding to support ongoing activities. The support from the Center to Reduce Cancer Health Disparities in fostering a participatory model of development has been landmark in the establishment and implementation of this initiative. This manuscript provides a historical background on cancer in the USAPI and prefaces 9 cancer assessments in this journal from the Commonwealth of the Northern Mariana Islands, Guam, American Samoa, Republic of the Marshall Islands, Republic of Belau, and the four states (Yap, Pohnpei, Kosrae and Chuuk) of the Federated States of Micronesia. **Key Words:** Pacific Islands (Trust Territories); Micronesia; Radiation-Induced Neoplasms; Medically underserved area, needs assessment, oncology services, Pacific Islanders, quality of health care, health services research

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Introduction

The US-associated Pacific Island jurisdictions (USAPI) refers to 6 entities:

Commonwealth

- Commonwealth of the Northern Mariana Islands (CNMI)

Flag territories

- American Samoa
- Guam

Freely Associated States (FAS)

- Republic of Palau (Belau)
- Republic of the Marshall Islands (Marshall Islands)
- Federated States of Micronesia (FSM), which is composed of 4 states—Chuuk, Kosrae, Pohnpei, and Yap.

Since the 17th century, these jurisdictions have been colonized by Spain, Germany, Britain, France, Japan, and/or the United States. Following the Spanish American War,

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Guam and American Samoa became unincorporated territories of the US, a status each maintains today. The other jurisdictions in Micronesia were designated by the United Nations in 1945 as strategic Trust Territories of the Pacific after the settlement of World War II. The US was entrusted with the health, education, welfare and development of these Pacific nations in return for the use of their geographically strategic lands. The US failed to adequately address the health, education and welfare needs of these areas and, over time, several jurisdictions developed into independent nations with compact treaties of free association with the US¹.

Health in the USAPI

Patterns of illness, disease, and health have changed dramatically in the USAPI over the last 60 years as a consequence of changes in the economy, western influence (consumed goods, such as food, tobacco and alcohol), globalization, war, US military presence in the region, and the US thermo-nuclear weapons testing program in the Marshall Islands. The USAPI are now in various phases of the epidemiologic transition, from infectious diseases to chronic illnesses and increased prevalence of diseases from man-made environmental hazards. The social production of illness due to crowding, poverty, environmental hazards, dietary changes, and social behavioral changes compel these jurisdictions to develop health care systems that meet these changing health demands¹.

Socioeconomic status has impacted the health of the USAPI. According to US Department of the Interior standards, about 25% of the population on Guam and 33% in CNMI live below the poverty level. For other areas, which live partly on subsistence (which is not factored in

to poverty determinations), the levels were much higher – about 63% in Belau; 68% in American Samoa, and more than 91% in the FSM².

Nearly all health indicators for Pacific Islanders living in the USAPI are worse than those in the United States, particularly in the freely associated states (FAS). For example, the average life expectancy at birth is as low as 62 years in some of the jurisdictions compared with 77.2 years in the US. Infant mortality is significantly higher in the FAS, ranging from 37.0 per 1,000 in the Marshall Islands to 16.7 per 1,000 in Belau, compared with 6.8 in the US. Diabetes, heart disease, tobacco use, alcohol abuse, and suicide are serious health problems in all of the jurisdictions. Parts of the region continue to experience cholera, typhoid, measles, pertussis, syphilis and dengue outbreaks and epidemics. Tuberculosis and Hansen's disease are endemic in certain jurisdictions. The Marshall Islands and the FSM have been designated by UNICEF as areas of "special need" in the Pacific because of malnutrition, vitamin A-deficiency and high infant mortality rates³⁻⁷.

As can be predicted by the epidemiologic transition, cancer has emerged as a critical contributor to morbidity and mortality in the USAPI. Cancer has become the first, second, or third cause of jurisdiction-specific mortality. The capacity of the health services of the USAPI to conduct surveillance, detection, prevention, treatment, and follow-up, and to mitigate the effects of the rising cancer burden is severely limited. The USAPI has entered late into the race to prevent, treat and control cancer. This paper outlines the history of cancer in the USAPI and describes the evolution of the present strategies to address cancer in the USAPI.

History of cancer data in the USAPI

The health information systems for all health conditions, including cancer, have been conspicuously lacking throughout the USAPI. In the 1940s, the Department of Health in Hawai'i managed the health data in the USAPI, followed by the Trust Territories Government in the 1960s⁸. As with other aspects of the health system, the technology, human resources, and complexity of the health information systems have been difficult to sustain¹⁻⁸.

Cancer registries in other areas of the Pacific were developed in Papua New Guinea (1958), Fiji (1965), New Caledonia (1978), and by the South Pacific Commission in 1981. With regards to the USAPI, a cancer registrar traveled to the FSM, Belau, the Marshall Islands and CNMI in 1983 as part of a pilot project to collect cancer data

for the years 1981 and 1982⁹. That pilot project did not go forward.

Comprehensive Pacific-wide cancer data monographs were published in 1985 and 1987 for the South Pacific Commission and the National Cancer Institute, respectively. The reports compared cancer rates in Polynesia, Micronesia and Melanesia. Of the USAPI, only American Samoa was described as having some site-specific cancer mortality rates. Micronesian data were aggregated^{9, 10}. Site-specific cancer rates for each jurisdiction of the USAPI were not possible to calculate and report with the available data.

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The 1985 Regional South Pacific Commission Cancer Monograph by Henderson et al., includes a comprehensive bibliography of Pacific cancer data and research up to 1985. Of the 182 scientific citations in 1985, only 3 citations were directed to countries of the USAPI. One of the three addressed thyroid cancer in a subset of Marshallese (Rongelapese) exposed to nuclear fallout¹². Most of the literature cited there reflected Pacific jurisdictions where cancer registries existed and where cancer tracking was made a priority.

Although comprehensive cancer registries have existed in the South Pacific since 1958, there were no cancer registries in any of the USAPI until 1997. The lack of health and cancer information systems was reaffirmed in the US Institute of Medicine report (1998), and again by needs assessments generated from the NCI Pacific Cancer Initiative in 2002. Without cancer surveillance systems in place in the USAPI, there has been little understanding of the epidemiology of cancer in each island nation or in the region as a whole. The same has been true of virtually all infectious and chronic health problems in the USAPI. The only current operational cancer registries as of September 2004 are in Guam and Belau.

Organizations outside of the USAPI have periodically collected health and cancer data from the USAPI, including regional reporting structures of the South Pacific Commission, the World Health Organization, and the Centers for Disease Control and Prevention (CDC). Notably, these reporting systems have not been linked to each other and have different reporting requirements⁸.

A heightened awareness of cancer

Several events have raised the awareness of cancer in the USAPI region. The US thermo-nuclear weapons testing in the Marshall Islands and the tobacco epidemic in the Pacific are two such events that have kept health officials alerted to increases in cancer rates.

The US Nuclear Weapons Testing Program. The US nuclear weapons testing program in the Pacific between 1946 to 1958 brought focus to environmental contamination with ionizing radiation and its potential effects on acute and latent cancer induction. There were 67 thermonuclear detonations tested largely above ground and in the atmosphere of the Marshall Islands over a 12 year period. These bombs had the equivalent explosive power of 7200 Hiroshima atomic bombs. The nuclear power from the testing era is equivalent to setting off 1.6 Hiroshima atomic bombs every day for 12 years. The immediate effects of beta burns, leukemias, and thyroid cancers have been documented for those who were accidentally exposed to direct nuclear fallout from the hydrogen bomb test¹¹⁻¹⁵. The long term latent effects of the ionizing radiation exposure from chronic exposure to environmental ionizing radiation are controversial and a source of concern for the people of the Marshall Islands and nearby USAPI areas^{16, 17}.

The nuclear testing directly affected many Marshallese, as well as workers from Kosrae, Pohnpei and Hawai'i who were hired to assist in the clean up of the contaminated nuclear testing sites. There has been concern voiced from the Guam congress regarding the potential health and cancer sequelae of the radioactive isotopes of strontium that was documented to have reached the shores of Guam via high altitude winds during the testing era. Questions of exposure and cancer risk from the testing era are also being generated from the governments of the Marshall Islands, Kosrae, Guam and others who were involved in the cleaning of contaminated testing sites.

An understanding of cancer rates in the USAPI and the association with the nuclear testing program is difficult without cancer surveillance systems. Cancer surveillance systems would establish baseline cancer rates and track site-specific cancer rates over time. Although the health of 253 Marshallese who received direct fallout from the hydrogen bomb test in 1954 have been monitored over time, the absence of an established national cancer surveillance system in the Marshall Islands or any of the other surrounding USAPI jurisdictions renders researchers incapable of comparing this cohort with the population before, during or after the nuclear testing program. The US Institute of Medicine recommended in 1998 that cancer surveillance systems should be in place in USAPI because of the concern for effects from nuclear testing and cancer³.

The smoking epidemic in the Pacific, like nuclear testing, will proceed unchecked without the help of cancer registries. Smoking was introduced to much of the USAPI by American GIs stationed in the area after World War II. US tobacco companies maintain aggressive tobacco advertising campaigns in this area. Although under the protection of the US as territories, the USAPI were not

given the same protections as the 50 US states with regards to tobacco warnings and advertising. American tobacco companies were allowed to market US cigarettes in many of the USAPI without warning labels until 1997, despite such labels being US-mandated in 1970. Similarly, the aggressive marketing to Pacific Islander youth and females would have not been allowed in the US¹⁸⁻²⁰.

The US tobacco companies were taken to court in 1997 by the Marshallese Government to recover government costs attributed to smoking. Many other Pacific countries and the world monitored this case against the US tobacco companies as it was the first international case that was allowed to go to court. The lack of health data, health finance data, and cancer data eventually led to the inability of the Marshall Islands to determine the financial cost to its government for smoking-attributable illnesses. Culpability of the tobacco companies was not the issue, but the lack of health data systems did prevent the case from being won²¹.

Attempts to describe USAPI cancer and cancer rates

The last decade has produced few publications on cancer in the USAPI. Since 1996 there have been several articles about breast cancer screening, knowledge and attitudes about cancer, and the cancer experience of American Samoans who live in American Samoa, Hawai'i and the continental US²²⁻²⁴. The CNMI did an initial analysis of cancer mortality rates in 1999¹⁹. In 2002, Guam's epidemiologist reported their 2002 cancer rates²⁵.

In 1997, a site-specific study was conducted in the Marshall Islands on the types of cancers prevalent there. Lung, cervix, liver and stomach cancers were reported to be the most prevalent. A subsequent 1999 study (mentioned next), identified a calculation error in the 1997 RMI study, which increased the 1997 incidence rates ten-fold²⁶⁻²⁸.

In 1999, the Nuclear Claims Tribunal (NCT), based in the Marshall Islands, funded a study to understand the cancer rates in the Marshall Islands and compare them to surrounding Micronesian countries. The study looked at the cancer information systems and available cancer data in the FSM, Guam, Saipan, Nauru, and Kiribati. The data from each jurisdiction presented a period prevalence of cancers. The results of this study are published in this issue of the PHD (Palafox, et al.; Ou, et al.).

Awareness to advocacy

In February 2001, both the Pacific Basin Medical Association (PBMA) and the Pacific Islanders Health Officers Association (PIHOA) made cancer prevention and control

a priority issue. Cancer was another illness that highlighted the large disparities in health status and health resources of the indigenous peoples of the USAPI when compared to the people of the US.

Advocacy through established communication channels with the US had not been easy because of the unique political histories and status of the peoples of the USAPI. The citizens of CNMI, Guam and American Samoa are US nationals; those of the FSM, Belau and the Marshall Islands have special status as dictated in their Compacts of Free Association with the US, allowing them access to the US without visas. This group has the highest per capita of any citizenry to have served/serve in Desert Storm and Iraq, and have been subject to the ill effects of the US Nuclear weapons testing program. Two of the 6 jurisdictions, American Samoa and Guam, each have a seat in the US House of Representatives but these positions are non-voting in Congress. Furthermore, the people of these countries cannot vote in US elections, thereby limiting their ability to represent their interests in the US government forum.

Many USAPI health organizations have been acting within the region to empower themselves. These organizations have rapidly moved the Pacific health interests forward through planning, program development, health and human resource development, research, collaboration and working toward common goals. Leading organizations include the Pacific Islands Health Officers Association (PIHOA), Pacific Basin Medical Association (PBMA), American Pacific Nurse Leadership Council (APNLC), Youth to Youth in Health (Republic of the Marshall Islands), and the former Pacific Basin Medical Officer Training Program. Additionally, the *Pacific Health Dialog* (PHD), the journal for community health and research in the Pacific, has become a crucial instrument in bringing Pacific health to the forefront of the scientific and international communities. These groups/initiatives have been the grassroots forces and the indigenous voices that have formed regional networks to coordinate the movement of health development in concert with federal agencies and their local government health departments and ministries.

Another method of advocacy has been to bring the issues directly to the US public and policy makers to increase awareness about the extreme conditions of health, including cancer in the USAPI. Partnerships have been established with US-based organizations that understand and work to address health and cancer disparities. Organizations in the United States that have been addressing issues in health disparities, social justice and distributive justice for minority people include the Intercultural Cancer Council (ICC), the Asian American and

Pacific Islander Health Forum, Asian and Pacific Islanders Cancer Survivors Network, Asian and Pacific Partnerships for Empowerment and Leadership, Pacific Resources for Education and Learning, John A. Burns School of Medicine (JABSOM) and Papa Ola Lōkahi. All of these organizations have recognized, embraced and advocated for USAPI health and representation.

During their annual national forums, often attended by thousands of participants, these organizations have actively included Pacific Island speakers in plenary sessions and advocated for speakers to share their own stories. Notably, as one means to support Pacific Islanders, the ICC changed its mission statement to specifically include the USAPI.

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In 1999, the President's Cancer Council (chaired by Dr. Harold Freeman) was presented with testimony on the cancer health disparities in the USAPI. Dr. Freeman acknowledged

the disparities and the dire conditions of health and cancer in the USAPI, and encouraged the development of databases to strengthen the case. In 2001, at an ICC conference in Washington DC, more information on the Pacific cancer dilemma was presented. Dr. Freeman committed his office, the Center to Reduce Cancer Health Disparities, to support the work that addresses Pacific cancer health disparities.

The Pacific Cancer Initiative

Over the next year, staff of the Center to Reduce Cancer Health Disparities (CRCHD) identified resources and partners in the National Center on Minority Health Disparities (NIH) and the Office of Minority Health to support the Pacific Cancer Initiative. Funding was channeled through Papa Ola Lōkahi, a Native Hawaiian health organization with a track record of advocacy and technical assistance in the Pacific, and ongoing collaboration with the Department of Family Medicine and Community Health at the University of Hawai'i. The goal of the Pacific Cancer Initiative was to address the cancer health needs in the US-associated Pacific by:

- 1) creating an indigenous team to articulate the cancer health needs of Pacific Islanders,
- 2) strengthening and sustaining community capacity, and
- 3) including Pacific Islanders in the programs and services of the National Cancer Institute and the National Institutes of Health that address those needs.

This collaboration initiated a partnership with Hawai'i and Pacific health care professionals to assess cancer health capacity and gaps. Assessment teams examined

regional and country-specific issues including health infrastructure needs, socio-economic factors, current sources of health services, quality of care and capacity of health care providers. These assessments provide the building blocks to discuss and prioritize regional and country specific needs. All nine assessments are presented in this issue of the *Pacific Health Dialog* and have contributed to developing strategic plans of action throughout the Pacific.

The process utilized for this initiative is one of inclusiveness, with representation from the clinical and public health sectors of each jurisdiction, including the 4 FSM states. The process also recognizes the people of the USAPI as the primary stakeholders of this initiative and supports partnerships that embrace and practice participatory interventions that include and value people of the USAPI as the decision makers and beneficiaries.

In year two of this initiative, the participating members formally established the Cancer Council of the Pacific Islands (CCPI), an indigenous regional forum for cancer. The members of the CCPI were appointed by their respective Ministers or Directors of Health. PIHOA, a consortium of health policy makers from the USAPI, has moved swiftly to support and advance the work of the CCPI, as has each of the USAPI Ministers and Directors of Health, and the Pacific Basin Medical Association. The CCPI members have met formally with Dr. Harold Freeman of the Center to Reduce Cancer Health Disparities, who, with his staff, learned of the strengths of their island nations and the challenges that impact on cancer health disparities. More detail about CCPI activities are provided in this journal by CCPI President, Kamal Gunawardane and Vice President, Yorah Demei.

Conclusion

Outcomes of the Pacific Cancer Initiative and the CCPI include a raised awareness about cancer health disparities of the USAPI; prioritization of cancer needs within the respective jurisdictions, and additional resources. These additional resources include a cooperative agreement between CDC and University of Hawai'i JABSOM to develop a comprehensive cancer control plan for the USAPI.

The US-associated Pacific Island jurisdictions are in various stages of readiness with their local comprehensive cancer control programs. The people of the USAPI were given resources (distributive justice) and the support to develop teams, approaches and strategies on their own terms. To this end, they are empowered to do what only they would be able to do in their Pacific jurisdiction and in the region. They have been brought to the table as equals by colleagues who understand—often first-hand—the dynamics of health disparity and social injustice.

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Ua o gatasi le futia ma le umele.
*While the fisherman swings the rod, the others
 must assist him by paddling hard.*

We must be of one mind in the undertaking.

Samoan proverb