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Cancer prevention and control in the USAPI: Participatory development and partnership – the voyage

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Abstract

Charting a course to achieve cancer prevention and control in several sovereign Pacific Island nations and US Pacific Island Territories has been a challenging and dynamic process. Partners and stakeholders from these communities have developed the infrastructure to achieve cancer control in the region. This narrative is about the Pacific Cancer Control voyagers in the region, who they are, where they hope to go, and the voyaging canoe on which they journey.

Cancer prevention and control is a formidable task in global environments that are geographically isolated, have limited healthcare resources and infrastructure, have small dispersed populations, are culturally isolated, and have little global political-economic influence. Many parts of Oceania share these characteristics. Participatory development and capacity building, using the untapped cultural and traditional assets of the people, and strategic partnerships are evolving to establish resource-appropriate cancer prevention and control in parts of Oceania. The history of the Cancer Council of the Pacific Islands (CCPI) and the Pacific Regional Partnerships illustrates some of the underlying principles and frameworks utilized to develop a foundation, the voyaging canoe, to reach cancer health equity in such environments. The work and structures may be relevant and applicable for other global communities addressing population cancer control in similar contexts of small populations distributed over a large area with multiple ethnicities, languages, and cultural histories.

The USAPI

The culturally diverse United States Affiliated Pacific Island (USAPI) Jurisdictions are made up of three United States (US) Territories (Guam, American Samoa, US Commonwealth of the Northern Mariana Islands [CNMI]), and three Compacts of Free Association (COFA), which includes the Federated States of Micronesia (FSM), Republic of the Marshall Islands (RMI), and the Republic of Palau (ROP). The estimated USAPI population is 415,000 people living on hundreds of remote islands, atolls, and islets (1–6), spanning over one million square miles of ocean, more than twice the area of the continental United States. This area crosses five time zones and the international dateline, and has more than a dozen distinct spoken Indigenous languages (Figure 1).

Health disparities in the USAPI

USAPI jurisdictions have some of the highest rates of chronic diseases in the world. Mortality from cardiovascular disease, cancer, diabetes, or cardiorespiratory disease between the ages 30 and 70 in the FSM was reported at 46.3% in 2021, the second highest in the world, compared to the United States at 13.6% (8). Four of the top 15 countries in which diabetes is the most prevalent are USAPI jurisdictions (9).

The risk factors for many preventable cancers, such as obesity (10), tobacco (11–17), and hepatitis B (18) are more prevalent in the USAPI compared to the United States. The top 10 countries with the highest prevalence of obesity are in the Pacific, and two are USAPI jurisdictions (10). Cervical cancer incidence is two to eight times the US incidence in the various jurisdictions. Liver cancer in Palau is 2.5 times the US rate. Twelve years of nuclear testing in the RMI adds to the cancer burden in the region (19). Mammography services are not accessible population-wide in the FSM, and access to regular cervical cancer screening in many of the COFA nations is limited (18). The cancer burden throughout the USAPI from 2007–2020 is shown in Figure 2 (18).

The USAPI jurisdictions have small populations, dependent island economies, rural communities, and populations with lived disparities. Whereas the United States is classified as a high-income country by the World Bank, six USAPI jurisdictions have at least 23% of the population with incomes below the 100% US federal poverty threshold (20). The USAPI per capita total expenditure on health (in purchasing power parity) ranges from US\$ 228 in Chuuk, FSM (21) to US\$ 1,990 in Guam (22), compared to the United States at US\$ 11,702 (23). The challenged socio-economic environment, high poverty rates (1,24–27), isolated island geography, poor healthcare access (18), low health literacy and education attainment (1,4,6,28,29), and the lack of a fully trained health workforce all contribute to health disparities, persisting chronic disease rates, and worsening health outcomes (30–33).

Organizing a partnership for cancer prevention and control in the Pacific region

Through barefoot advocacy with passionate academic and funding partners, the USAPIs have established the Cancer Council of the Pacific Islands (CCPI) (Figure 3). The

CCPI is a registered 501(c)(3) organization since 2007, with the Pacific Island Health Officers Association (PIHOA) as its designated fiscal agent. PIHOA is an overall advisory body to the comprehensive cancer control (CCC) process. The PIHOA Board and Associate Members are the USAPI Ministers, Secretaries, and Directors of Health. As per the CCPI bylaws, an executive committee comprises an elected President, Vice President, and Secretary-Treasurer. The CCPI Board of Directors consists of two or more individuals appointed by the respective Ministers, Secretaries, and Directors of Health, representing each USAPI from the clinical and public health sectors. The CCPI reports to their jurisdiction's health leadership, and the CCPI Board of Directors are the final decision-makers accountable for implementing the RCCC plan. The CCPI designated the University of Hawai'i Department of Family Medicine and Community Health to serve as the Secretariat/Management to provide technical assistance, maintain the CCC process, operationalize the cancer registry, and assist in cancer-related advocacy at the United States, Hawai'i, Pacific regional, and international levels. CCPI works with partners to manage and address cancer risks, incidence, and mortality disparities on a regional basis. It also strives for public health systems strengthening to achieve economies of scale, standardized reporting, and a unified voice for the USAPI by linking comprehensive cancer control efforts, USAPI cancer registries, and other related non-communicable diseases (NCD) efforts (34).

Regional Comprehensive Cancer Control (RCCC) Plan for USAPI

Collaborative RCCC plans from 2007–2027 are guided by principles of participatory development (35); health workforce development and training; resource-appropriate technology; multi-level and multi-sector stakeholder coalitions; health system capacity building; community engagement; cultural safety and indigenous ways of knowing; and a socio-ecological theoretical framework to align incentives and “ownership” of population health.

The RCCC advocates for the CCPI's resource development in cancer and NCD prevention among US National, Regional, and International organizations, including the World Health Organization (WHO) and the Secretariat for the Pacific Communities (SPC). The individual USAPI CCC Programmes contribute to the RCCC, with the membership to meet at least biannually to address regional cancer priorities.

Implementing the RCCC Plan involves collaboration with other regional affiliate organizations as the region moves to improve basic public health infrastructure, including capacity in different areas that impact NCD control, including cancer. Effective collaboration, shared vision, an agreed-upon structure for decision-making, representative equal voting, informed and shared decision-making, open communication, and clearly defined roles and responsibilities are significant operating principles established and utilized by the CCPI. Two stakeholder coalitions contribute to the CCPI:

- **Regional Cancer Coalition:** CCPI members who are part of their coalitions provide regional direction to the RCCC efforts. Prioritization of the RCCC plan activities is time- and resource-based and addresses core foundational

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issues to achieve long-term sustainability. The plan is adapted according to new information, policies that affect the region, other opportunities, and new partnerships.

- Local Cancer Coalitions: Each jurisdiction has a diverse local multisectoral community coalition, which the jurisdiction's CCC coordinator facilitates. The coalitions assess their community cancer-related issues and create and implement an assessment-informed and culturally-appropriate cancer plan using a community-based participatory approach, followed by an evaluation of the plan activities. This approach allows individuals and their communities to provide input and become vested in the interventions.

The regional approach has borne successes in cancer registration, cancer case geospatial mapping, palliative care curriculum, cancer survivorship-related resource maps, community CCC programme partnerships, analytics training for public health and clinical personnel, and impact assessments of community-driven projects on cancer prevention and control.

Pacific Regional Central Cancer Registry (PRCCR)

The PRCCR, located at the University of Guam, has developed and maintained population-based cancer registries in the USAPI jurisdictions, with the assistance of the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries and the Hawai'i Tumor Registry, reporting cancer data starting in 2007. The PRCCR and its partners provide training, technical assistance, and quality assurance to ensure reliable and complete information. The PRCCR advocates for a system-wide improvement in health information, medical records and mortality data and shares local data resources to enhance jurisdictional CCC and NCD efforts.

The primary tasks and responsibilities of the PRCCR are to develop:

- cancer registries where the data is controlled and owned by each jurisdiction;
- systems and policies that ensure proper identification, reporting, and recording of all cancers in each USAPI jurisdiction;
- capacity and infrastructure for each USAPI jurisdiction to manage the rigorous data collection and entry required of a cancer registry;
- a cancer registration system that is sophisticated yet flexible and sustainable.

The Racial and Ethnic Approaches to Community Health (REACH) (2014-present) and Pacific Center of Excellence in the Elimination of Disparities (Pacific CEED) (2007–2013)

The USAPI REACH actively collaborates with the RCCC, the USAPI CCC Coalitions and Programs, and the PRCCR. Since 2014, the REACH strategies have focused on local policy, systems, and environment (PSE) – nutrition, physical activity, tobacco, and community clinical linkages interventions – to improve population health in the USAPI.

- Approximately 278,000 people benefited from tobacco-free environment interventions at worksites, malls, and schools.

- Almost 80,000 people had better access to healthy beverages through water and coconut water policies at churches and schools.
- Over 128,000 people benefited from healthy nutrition interventions at stores and farmers' markets.
- Over 27,000 people had better access to be more physically active.

Pacific CEED aims to reduce breast and cervical cancer disparities in the USAPI and among USAPI residents in Hawai'i through innovative community projects created to document and disseminate promising practices for replication. Forty-six projects have been funded, including resource-appropriate minimum standards of practice for breast and cervical cancer across the prevention-to-care cancer continuum; health assistant and women's groups training to increase breast and cervical cancer screening education and coverage; assessed policies related to the WHO Framework Convention on Tobacco Control; palliative care training; and exercise programmes.

Pacific Against Cervical Cancer (PACe) Project

The CDC and PIHOA-funded PACe Project is designed to meet the WHO cervical cancer elimination goals in the USAPI through sustainable resource-appropriate technology. The primary objective is to increase the capacity of healthcare workers to prevent and control cervical cancer via enhanced evidence-based public health screening practices. The project initially focused on clinician and self-collection primary HPV DNA testing targeting underscreened women aged 30–64 in Guam and Yap State, FSM, with a plan to apply lessons learned to develop similar programmes across the USAPI.

Working with a participatory development framework with the health departments and healthcare providers, laboratory capacity using existing platforms for HPV DNA testing, and colposcopy and thermal ablation training is provided.

- Guam has a complex health system with public, private, and non-profit organizations supporting cervical cancer prevention services. A facility and service readiness assessment was conducted at five Guam facilities. Pap smears were the primary mode of screening in Guam. The project has continued to increase awareness of screening guidelines, develop pathways for primary screening using HPV testing, and build the capacity for local providers to manage positive cancer screening results.
- With Yap having a central health system, there was unified cooperation from the clinic, laboratory, and health department staff for self-collected HPV testing. From 2022 to 2024, over 1200 women aged 30–50 were screened using hrHPV testing methods; 62% had never been screened before, and 168 HPV positives (HPV+) were identified. Based on current progress, the WHO goal of screening 70% of women for cervical cancer will be achieved by 2030. With improved vaccine and screening rates, cervical cancer elimination can be achieved by 2048.

Pacific Cancer Telehealth Programme

The programme aims to strengthen local health system/community collaboration around telehealth and cancer control, provide cancer-related education and cancer case management opportunities for local healthcare providers via telehealth platforms, and train community health workers to improve access to care for vulnerable populations. The USAPI-centric continuing medical education (CME) sessions are provided to health providers and advocates with case studies intertwined in didactic education sessions. Sessions range from cancer prevention to palliative care. Since 2019, there have been 52 sessions, 17 community health worker training sessions, 615 total attendees, and at least 475 CME credit hours provided to healthcare providers.

Challenges for the Pacific Island Region

The last 25 years of the Pacific cancer control voyage have witnessed natural disasters, workforce challenges, financial shifts, and leadership changes. Typhoons have devastated Guam (36), CNMI (37,38), and Yap (39) shutting down the governments for months. Rising sea levels in the RMI and FSM threaten food security (40–42). Harmonized collaboration across the USAPI, navigating local traditional systems and government bureaucracies in the territories and sovereign nations is essential while ensuring balanced participation across a large geographic area, multiple time zones, and nuances of a multicultural community.

Common challenges include:

- Disparity of social determinants of health – Most US communities are unaware of healthcare and health status disparities in the USAPI. Compared to the United States, the USAPI continues to have the highest burden of adverse social determinants of health.
- Healthcare systems frequently manage healthcare crises – Health staffing is stretched to prevent and manage infectious disease outbreaks and natural disasters. Healthcare budgets for each USAPI are a small fraction of the US per capita healthcare expenditure, and health systems are strained under the toxicity of the NCD epidemic (43). Historical under-investment in healthcare human resource development, training, and retention has contributed to a workforce shortage. Access to systemic therapies is limited. Only Guam and CNMI having on-island oncologists, with only Guam have on-island radiation therapy. Restrictions for government-supported tertiary healthcare services such as advanced cardiac, surgical, or cancer care are often necessary due to limited healthcare budgets (18).
- Geographic and political isolation and cost of travel – Wide dispersion across the Pacific Ocean poses logistical challenges in healthcare delivery across five time zones and crossing the international date line. Virtual health communication and training are limited in several Pacific jurisdictions due to low-quality digital bandwidth. On-island technical assistance and training visits are essential for community capacity building, fostering and maintaining relationships, health systems strengthening, basic disease and risk factors surveillance, and working

toward the sustainability of project activities. Limited resources to expand healthcare reach to distant outer-island communities include the need for consistent and reliable air and sea transportation to the neighbouring islands.

Opportunities for the Pacific Island Region

The CCPI, its partners, its infrastructure, Pacific Regional Cancer Registries, and the Cancer Plans provide a foundation to identify and integrate other mission-aligned opportunities.

Promoting cancer health equity in the region:

- leverage existing networks to address food insecurity and access to healthy food, clean water, clean air, healthcare, cancer survivorship services, pedestrian-safe built environments, and policies for active living to confront diseases of affluence and health consequences of Westernization;
- develop more extensive and robust collaboration with regional, US national, and international entities and policymakers to address policy and regulatory barriers and leverage additional resources to achieve the RCCC Program objectives and Pacific-wide cancer data sharing;
- Incorporate programme planning evaluation and epidemiology to ensure sustainable and effective policy, systems and environmental interventions, including measures of PSE interventions on the effects of population health equity in future regional coalition assessments (44).

Research for innovative solutions:

- The USAPI community-engaged and community-relevant cancer research can identify and develop interventions to address prevention, screening, treatment, policy, or behaviour challenges. The University of Hawai'i Cancer Center and the University of Guam have developed cancer research capacity-building initiatives. There are future plans to collaborate with cancer research institutions in New Zealand and Australia.

Sustain the efforts to reach cancer equity:

- harmonize research grants in the domains of health disparities, health equity, cancer, and NCDs;
- recognize the interdependence of different organizations and programmes in the region and integrate regional health promotion and disease prevention efforts into the RCCC purpose and mission, as well as engage stakeholders within cancer and NCD work to highlight overlapping goals;
- continue enhancing existing systems that collect and report quality cancer data to guide the policy, systems and environment (PSE) interventions and program planning;
- Future plans and expectations:

- Strategy development and organizational structure – foster organizational and structural changes within the Departments and Ministries of Health to link cancer initiatives with regional and jurisdictional NCD strategies, NCD risk-based approaches, and integrated implementation plans.
- Human resources development – institutionalize in-service education and training, with enhancement through accreditation of training courses in the USAPI community college system, ensuring all content clearly addresses non-siloed approaches and linkages to NCDs.
- Innovations and promising practices – fund, document, and disseminate innovative projects and promising practices that are culturally relevant, community-informed, and systems-based; address health disparities and inequities; and reduce factors contributing to chronic disease risk.
- Technical expertise – provide and fund technical assistance and initiatives that promote skills and infrastructure development and an appreciation of, and demand for, improved accountability, including a robust telemedicine capability.

Conclusion:

Master Yapese Navigator Mau Pialug stated to a small group, including the author NAP, “Sail when you are ready and when the conditions are right. Voyage when you are invited into the star house.” Ready, as he meant it, means when the weather and winds are favourable, the right canoe is strong and has been prepared, when the sailors are trained, and when the navigator and ship’s captain have a plan. The star house refers to a specific direction or a star in the traditional Pacific celestial maps. An invitation into a celestial house suggests that there is a larger purpose and intentionality to the direction of the voyage. The voyage is not a cruise or entertainment. The celestial house entails reflecting on the spiritual, opportunity, and danger of sailing – especially in uncharted waters. And it has an element of “you will know when you are invited”. There may be elements of discovery, acquiring new resources, getting to safety, warning, and uncertainty.

Developing effective cancer prevention control in the Pacific is necessary as many parts remain uncharted waters. The principles and general approach have been participatory, capacity building, and guided by traditional Pacific wisdom and knowledge. The USAPI CCPI has begun its voyage and has been invited to a destination. It is with great expectation that other Pacific or Global regions can use the knowledge, work, and star charts used by the CCPI and USAPI region. ■

Biographies



Dr Neal A Palafox is a Professor of Family Medicine and Community Health at the University of Hawai'i John A Burns School of Medicine and Associate Director of the Diversity, Equity, and Inclusion Office at the University of Hawai'i Cancer Center. His focus has been on reducing health disparities in Hawai'i and the US Affiliated Pacific Islands. This work has involved health/healthcare capacity building through workforce development, systems-based development utilizing a community-based participatory approach, establishing a Regional Pacific Population-Based Cancer Registry, establishing the Cancer Council of the Pacific Islands, and developing a Pacific Regional Cancer Prevention and Control Network.



Dioreme Navasca earned her MPH at the University of Hawaii and has over 10 years of experience in health policy management, community education, and community-based participatory research. Ms Navasca was engaged in various research and public health intervention programmes. She served as a Regional Programme Officer at PIHOA, a non-profit organization led by and represents the collective interests of the USAPI health agencies. As a Programme Specialist, she coordinates and facilitates technical assistance and capacity-building across multisector engagements on project planning, implementation, evaluation, and dissemination. Her interests are women's health, legal epidemiology, health equity, and telehealth in rural settings.



Dr Lee Ellen Buenconsejo-Lum attended Stanford University for her Bachelor of Science in Biology. She then completed medical school and family medicine residency training at the University of Hawai'i John A. Burns School of Medicine (JABSOM). She is a full professor at the JABSOM Department of Family Medicine and Community Health, and Principal Investigator of the Pacific Regional Central Cancer Registry, and co-PI of the USAPI Pacific Regional Comprehensive Cancer Control Program. Dr. Buenconsejo-Lum's scholarly work has included building health system capacity to address cancer health disparities (including telehealth) and improving prevention and screening for cervical cancer.



János Baksa attended the University of Pécs, Hungary, for his Masters in International Business Management. Janos is a seasoned Programme and IT Manager at the University of Hawai'i's Department of Family Medicine and Community Health, where he manages both the Pacific Regional Central Cancer Registry and Pacific Regional Central Cancer Control Programmes. With over 20 years of work experience, János was fortunate enough to be involved in projects ranging from large-scale European health infrastructure development projects through designing public health services for minority populations to assisting in designing cervical cancer screening databases for the US Pacific Islands.



Aileen Tareg, DrPH, is a health education specialist working under the Racial and Ethnic Approaches to Community Health project with the University of Hawai'i's Department of Family Medicine and Community Health, Pacific Cancer Programmes. Aileen holds a BA in Psychology from Walla Walla University and a Master's and Doctorate in Health Education from Loma Linda University. With over 20 years of practising public health and over a decade of experience in chronic disease prevention in Yap State in the Federated States of Micronesia, where she is from and based, she actively supports community health, most prominently as the Chairperson of the Wa'ab Healthy Lifestyle Coalition.



Youngju Jeong has served in various roles in the USAPI public health initiatives for over 15 years. He began as an administrative and budget officer for the CDC's Racial & Ethnic Approaches to Community Health (REACH) projects. He transitioned into data analysis and evaluation for the Pacific Regional Comprehensive Cancer Control Program and Regional Central Cancer Registry. He also manages the finances and evaluation for the CDC REACH projects and the Pacific AIDS Education and Training Center – Hawai'i and USAPI. He provides technical support and training in cancer data analysis and reporting to registrars and stakeholders across the Pacific.



Dr John Ray Taitano was born and raised on the island of Guam. His parents instilled in him pride in his Chamorro heritage, humility, and, above all, love for family. He graduated from the University of Hawai'i School of Medicine. He has served as President of the Guam Medical Society, President of the Guam Memorial Hospital Medical Staff, President of the Guam Commission on Licensure, President of the Veterans Advisory Council, Chairman of the Guam Board of Medical Examiners, and is currently Chairman of Department of Medicine and was re-elected President of the Cancer Council of the Pacific Islands.



Martina Reichhardt attended the University of Papua New Guinea for her Bachelor of Journalism. She has been the Yap Comprehensive Cancer Control Program Director since 2007 when the first CDC cancer grants were awarded. Her work has covered the cancer care continuum from prevention to survivorship efforts in a limited resource setting. Her programme was awarded the National Association of Chronic Disease Directors 2024 Community Impact Award for their work with the University of Hawai'i and other partners in piloting the HPV screen, test, and treat programme in Yap for cervical cancer under the Pacific Against Cervical Cancer project.



X-ner Luther is the National Comprehensive Cancer Control Program Coordinator and National Non-Communicable Disease Section Chief at the Federated States of Micronesia Department of Health and Social Affairs. Previously, he was the Pohnpei State Comprehensive Cancer Control Coordinator at their local Department of Health Services. He is passionate about improving the overall health and well-being of the Micronesian communities.



Mavis Nitta holds a Master's in Public Health from San Jose State University. She is the Program Manager of the CDC's Racial and Ethnic Approaches to Community Health and Pacific Against Cervical Cancer projects at the University of Hawai'i's John A Burns School of Medicine. She has over 20 years of experience working with health departments and community-based organizations to build their capacity to address cancer and non-communicable disease disparities. She has also collaborated with USAPI public health leaders, staff, and advocates to generate policy, system, and environmental changes that benefit the national, state, and local communities.

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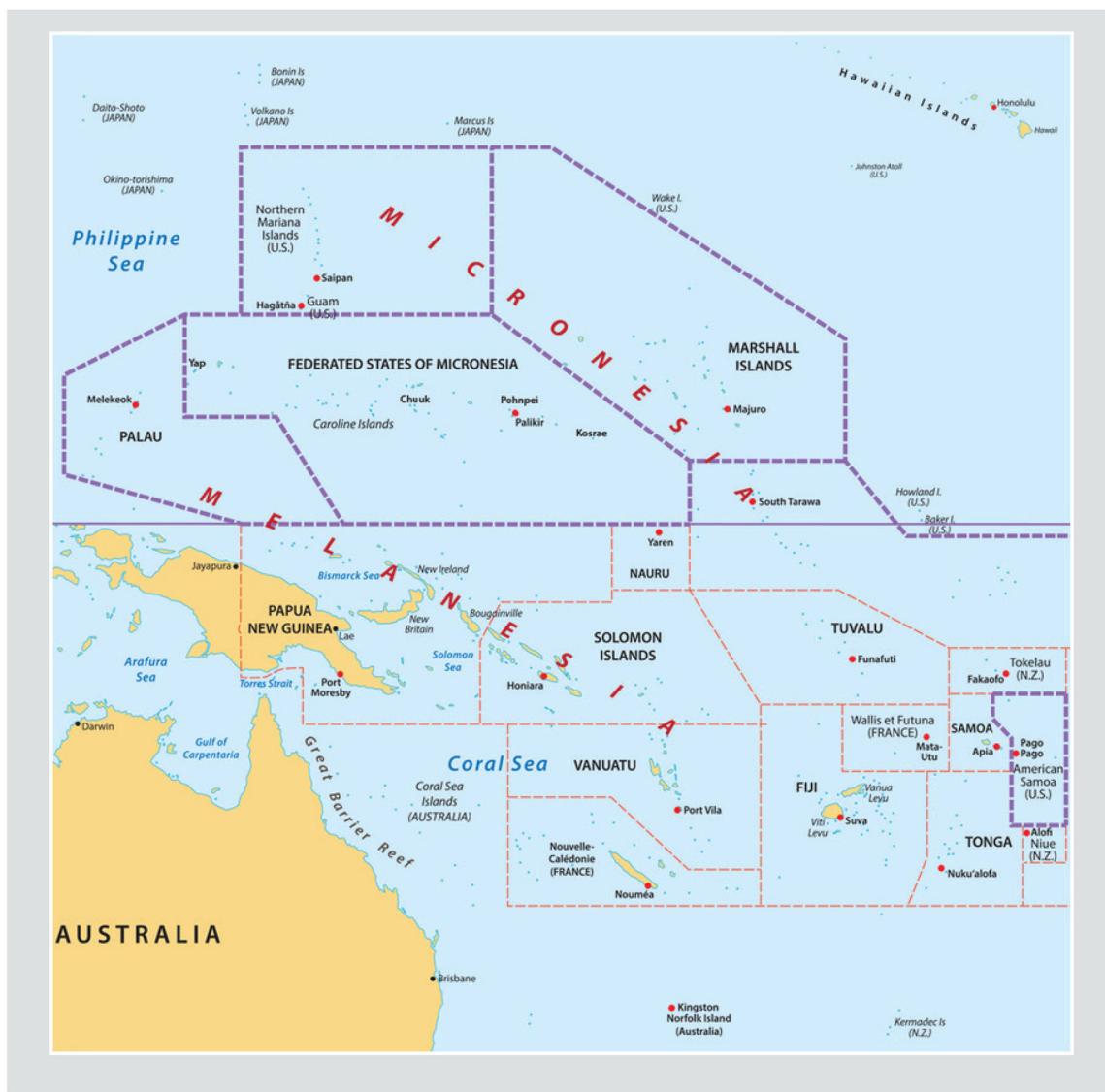


Figure 1:
Map of the US Affiliated Pacific Islands (7)

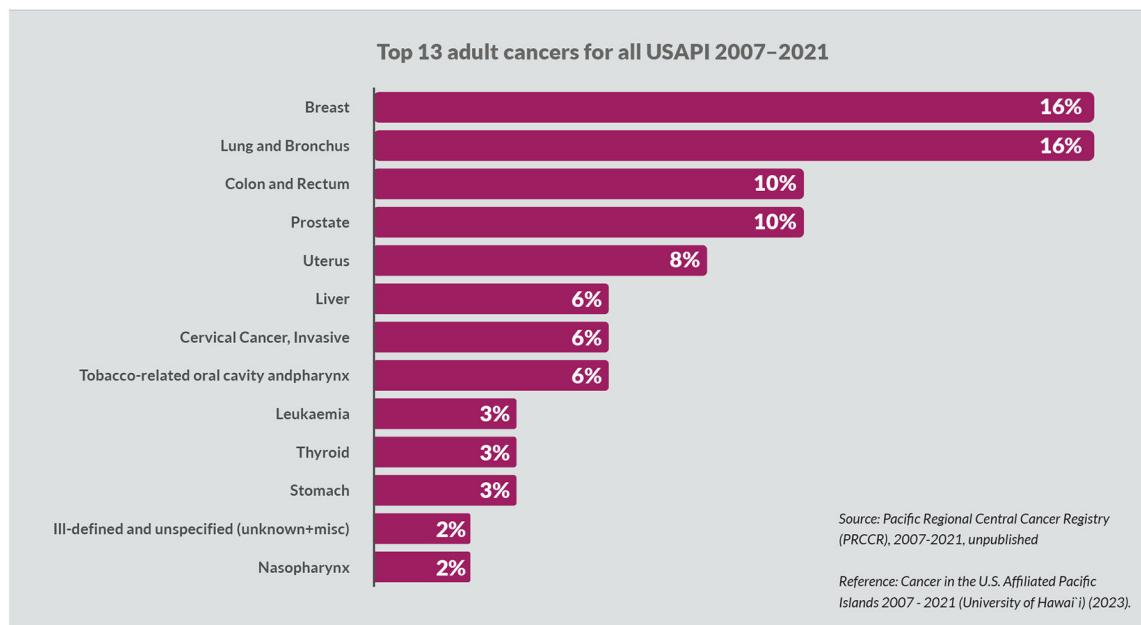


Figure 2:
Burden of cancer in the USAPI (18)

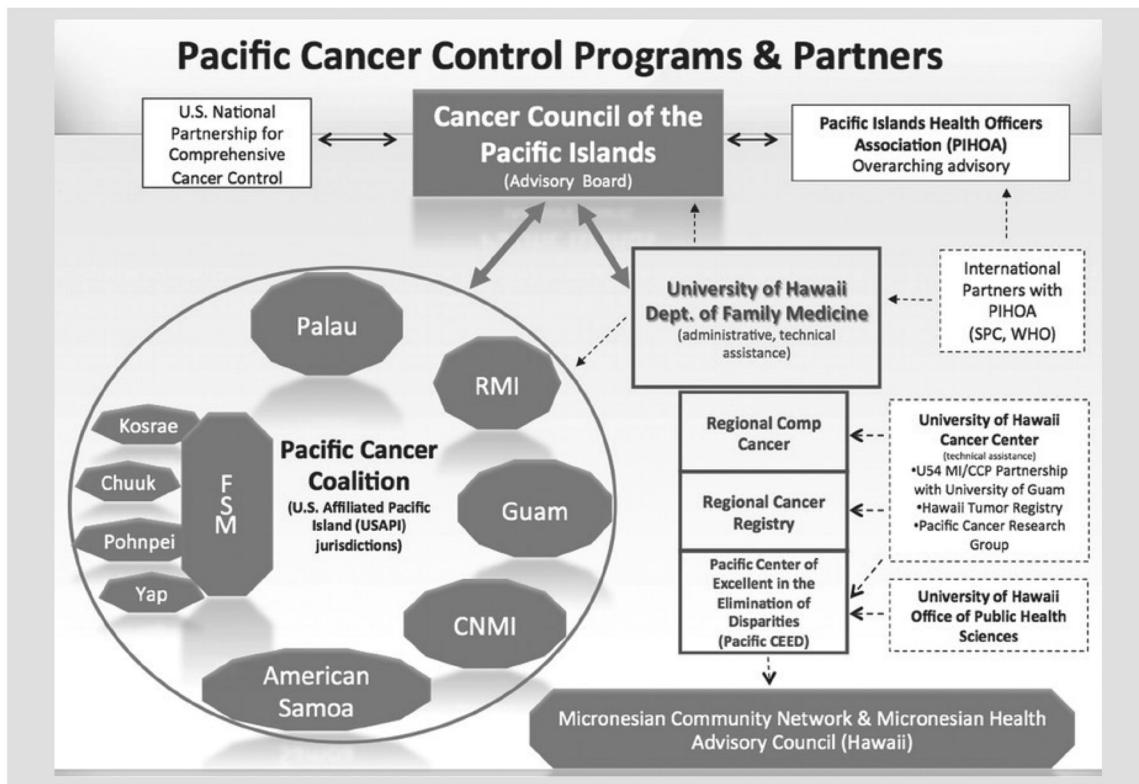


Figure 3:
USAPI collaboration and partnership