Regional Cancer Registries: An Option for Resource Limited Settings

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Summary
The US Associated Pacific Island Nations (USAPIN) are developing cancer data and surveillance infrastructure as a component of their comprehensive cancer control plans. Various cancer registry systems were assessed for adaptability, sustainability, and technical feasibility in resource limited, relatively small island populations. Many jurisdictions lack systematic cancer data collection or coding, standardized medical record procedures, and policies relating to data collection. The medical infrastructure to appropriately diagnose, stage and treat cancer is also limited. The USAPIN are working towards developing a more robust cancer data collection infrastructure and to utilize a web-based regional registry that allows for local ownership of data, fosters local capacity building, and accommodates modifications to meet local needs.

Introduction
The US Associated Pacific Island Nations (USAPIN) consist of a commonwealth, 2 flag territories and 3 freely associated states (FAS): The Commonwealth of the Northern Marianas Islands (CNMI), flag territories of American Samoa and Guam; and the FAS of the Federated States of Micronesia (FSM), – which consists of the states of Kosrae, Pohnpei, Chuuk and Yap – The Republic of the Marshall Islands (RMI), and the Republic of Palau (ROP). The island nations 480,000 people are scattered over a Pacific Ocean landscape that is more than twice the size of the US. The 33 atolls of the RMI alone cover 750,000 square miles of ocean. Each of the USAPIN has unique cultures and languages.
Tremendous health disparities exist between the USAPIN and the United States (US). Longevity is more than 12 years less than the US in the FAS, and infant mortality is 2-3 times greater. In 1998, the health expenditure per capita in the US was $4500¹ whereas only $92 was provided to Chuuk state FSM.² In 2005, the US healthcare per capita health expenditure was close to $5300 and the USAPIN ranged between $110 in the FSM to $700 in Guam. These USAPIN continue to have significant burdens of both communicable and non-communicable disease. Cancer has been noted to be in the top three causes of mortality in all USAPIN. There were no cancer registries in the USAPIN until 1997, whereas several South Pacific non-US associated Pacific nations had functional cancer registries since the 1970s.

Comprehensive cancer infrastructure assessments conducted in 2002-03 by the University Of Hawaii Department Of Family Medicine and Community Health (DFMCH) found a limited capacity for cancer surveillance, cancer prevention, and early detection or treatment programs in many of the USAPIN. The capacity to collect accurate cancer data is limited³ in most settings with current data collection methodology and because of limited reporting policies and procedures. The challenges with infrastructure, resources and health workforce capacity have helped prompt the need for coordinated, regional efforts toward reducing the burden of cancer.

**Methods**

As a component of comprehensive cancer control planning, the U.S. Associated Pacific Island nations (USAPIN) undertook a critical assessment of the infrastructure and local capacity to maintain a functional cancer registry. Standardized surveys were conducted via phone, e-mail, mail or fax. Onsite visits were conducted to assess local USAPIN cancer data system infrastructure, support, and function. Key informants included hospital administrators, physician leaders, medical records, laboratory staff and policy makers. They were asked to provide their insights regarding the development, structure, operations, and sustainability of a cancer registry.

The CDC-NPCR, NCI-SEER, WHO-CanReg⁴, and other cancer registry systems were evaluated to determine which registry system best fit the needs of the small island populations of the USAPIN. Operational requirements and track records of the various registries in the USAPIN, the Pacific, and other geographically dispersed areas were examined. Officials who work with, support and have developed the cancer registry systems at the CDC, WHO, NCI, and the USAPIN were engaged. The cancer registry systems were assessed for flexibility, adaptability, support (technical and financial), relevance, ownership and access to data, and sustainability.

Results of the surveys and site visits were discussed with the regional cancer control oversight organization (Cancer Council of the Pacific Islands), local cancer coalitions, the regional comprehensive cancer control coalitions, the regional health policy / decision-making organization of the USAPIN (Pacific Island Health Officer Association – PIHOA)
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Results

Table 1 compares some of the existing registry infrastructure and coding methods now in use. Table 2 describes data sources and flow. Many jurisdictions lack uniform cancer coding, standardized medical records procedures and documentation. Data collection and tracking is not performed systematically in most jurisdictions. Policies relating to data collection are not in place or not enforced. No certified tumor registrars exist in the USAPIN. Guam and Palau have begun developing cancer registries in the last 9 years. Many of USAPIN have multiple sites of cancer data collection, and some have two cancer registry systems in competition at the same site. The numbers of cancer cases diagnosed per year and other infrastructure challenges make it neither feasible nor practical to have a central cancer registry in each jurisdiction.

A sustainable and functional cancer registry will be developed in two
synergistic phases. Initially, the capacity of site-specific health information systems infrastructure, cancer screening/diagnosis/treatment must be improved. Secondly, a registry system that meets the needs and fits the infrastructure of the USAPIN should be developed.

This evaluation, supported by regional consensus, has led to plans to work toward a web-based regional cancer registry that would accommodate the present challenges, allow for local ownership of data, and provide technical support and software that could be modified to fit local needs. Whereas maintaining local fully trained registrars is not feasible at this time, shared USAPIN based traveling registrars, called circuit riders, would provide the regional expertise and training. A web-based format would take advantage of current technology to cover the geographically isolated populations. The CDC/National Program of Cancer Registries Registry Plus™ best fits the present needs of the USAPIN.

Conclusions

Significant challenges in cancer data management exist throughout the USAPIN. Additionally, capacity to provide basic screening, diagnostic and treatment services is lacking in some areas. While the individual jurisdictions develop their comprehensive cancer control (CCC) plans, a regional CCC plan includes development of a regional registry. Regional resources will be pooled to create a single web-based regional registry with oversight within the USAPIN. Capacity building will be emphasized in order to attain a minimum set of regional standards for cancer data collection and tracking. Circuit riders would give support, provide training, and collect data in the various jurisdictions. The variance in individual jurisdiction infrastructure will be accommodated so that each jurisdiction can develop at its own pace. As the infrastructure needs are great, it is expected that development of a robust registry for the region will be a 10-15 year project. Epidemiological trends, patient outcomes, and patient trends derived from the registry will guide resource utilization and cancer policy development.

References


