



AMERICAN SAMOA

Comprehensive Cancer Control Plan 2007-2012





Talofa and Greetings to all our residents,

The American Samoa Community Cancer Coalition is pleased to provide the first Comprehensive Cancer Control Plan for American Samoa. With the establishment of cancer being diagnosed as the second leading cause of death on our island, a call for action was made and the brainstorming for this plan began in June of 2004. In order to produce this plan, the American Samoa Community Cancer Coalition examined the current cancer burden and disparities that have been affecting the territory and established priorities for the next five years. This plan outlines the basic foundation of how cancer prevention, early detection, diagnosis/treatment, quality of life, data collection/surveillance and costs will be conducted in American Samoa.



This plan only represents the beginning of Comprehensive Cancer Control in the territory and will help to *coordinate* and *integrate* all resources locally and nationally. By streamlining our resources this way, we begin to fill in “gaps” in our health care system. Gaps that individuals slip through and eventually don’t receive the proper or necessary treatment that they deserve.

With this plan, we also make two commitments to all of our residents. These commitments are the guiding principles for the American Samoa Community Cancer Coalition. First is to continue with our best efforts as a community based organization to fill these gaps, either on the national or local levels, for the future of our residents. Secondly, to continue on our foundation that Comprehensive Cancer Control is structured on partnership and collaboration. We hope that as you read this plan you create a commitment of your own that helps yourself, or others on island, fight this disease.

Fa’afetai Lava,

The American Samoa Community Cancer Coalition Board of Directors

Va’a requested that this page be included for REFERENCE. Please ask him if it is ready.

Thanks.



Evaluation Plan

Evaluation is a key component of any successful program. Throughout planning, various evaluation methods have been utilized to guide the process and positive changes have been made as a result. Evaluation will continue to be critical as we take the next step and begin to implement our plan.

The evaluation plan will address three core areas for successful implementation of our comprehensive cancer control plan:

1. American Samoa Community Cancer Coalition
2. American Samoa Comprehensive Cancer Control Plan
3. Implementation Process

More specifically, the evaluation committee will assess on a quarterly basis:

- Infrastructure needs and capacity
- Level of support
- Gaps in data
- Partnership composition and satisfaction
- Burden of cancer
- Progress in achieving program objectives

Strategies for evaluation will reflect the measures for specific activities within each component of the plan. Results of this comprehensive evaluation will be compiled into an annual report and shared with the coalition and other local, national and regional partners. More importantly, the results will serve to improve all aspects of the CCC program, implementation process and ultimately, the burden of cancer in American Samoa.

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Message of Commitment



Talofa and Greetings to all our residents,

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Fa’afetai Lava,

The American Samoa Community Cancer Coalition Board of Directors

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- on island that deal in cancer diagnosis and treatment
- Does the strategic health plan (developed by LBJ) include upgrading current services available and/or bring new technologies to the territory

6.1B

In year two, staff from ASCCC, LBJ, and DOH will conduct a feasibility study that will review the reimbursement of services at LBJ Tropical Medical Center. The study will include but will not be limited to:

- What is the average cost of diagnostic services available on island (biopsies, x-rays, ct scans, etc.)
- What is the average cost of reimbursement that the patient is responsible for, for services provided on island
- What is the cost of non-reimbursable services that are available, and may be available in the first five years of implementation, on island (e.g. social workers, patient navigation, psychological services)
- Is there funding for those who are below the federal poverty level and for those above the federal poverty level?
- What are the barriers that limit the access to care due to the need of insurance coverage
- Identify the necessary infrastructure that would be needed to offer the highest level of care in cancer diagnosis and treatment at the LBJ Tropical Medical Center.



Cost Goals and Objectives

Lessen the financial impact of cancer treatment on patients and their loved one.

A financial burden can best be described as something that is worrisome or oppressive that is related to finance or money.

In most cases, cancer can have a devastating financial impact on survivors and their families. Normally, there are two types of expenses that are associated with cancer care:

1. Direct Medical Costs
Related Non-Medical Expenses (e.g. travel, child care, housekeeping assistance, etc.)

Direct medical costs are a result of cancer treatment (e.g. physician's fees, hospital expenses, and pharmacy bills). Most of these costs are covered by a basic health insurance plan.

Most non-medical costs related to cancer care are not covered by health insurance. This makes the patient and/or patient's family responsible for the overwhelming and rising cost of that particular treatment.

The financial impact on those who do not have adequate health insurance, or do not have savings or other financial resources, can be especially harmful to a patient's mental health, which can ultimately affecting their quality of life during treatment.

Although it is known that medical care for cancer diagnosis and/or treatment can be quite expensive, most people are not prepared for financially until they are faced with mounting bills.

Cost of Cancer Treatment and Diagnosis Nationally

- 84.3% of the population in the United States has health insurance (2005 U.S. Census)
- Median household income \$44,389.00 (2005 U.S. Census)

- Average household size
- State legislation requiring employers to provide health insurance to employees.
- In 2002, average cost of colorectal cancer treatment six months after diagnosis was \$27,658.
- In 2002, average cost of terminal treatment for colorectal cancer was \$30,815.

Cost of Cancer Treatment and Diagnosis in American Samoa

- The only United States territory practicing socialized medicine.
- Approximately .5% of the population currently has Medicare Insurance.
- Median household income \$18,349.00 (2000 U.S. Census).
- Colon cancer was ranked 5th among cancer deaths from 1998-2001.
- Average household size is approximately 6.02 persons (2000 U.S. Census)

Objective 6.1

Ensure the availability of cost effective cancer treatment that can be made available to our underserved population.

Strategies

6.1A

In year one, staff from ASCCC, LBJ, and DOH will conduct a feasibility study specifically answering the question if cancer treatment on or off island would be more cost effective. The study will include but will not be limited to:

- Location of diagnosis (on or off island)
- What is the national average cost for cancer treatment (e.g. chemotherapy, radiation, medical doctors, etc.)
- What are the basic services that comprise cancer diagnosis and treatment
- What are the current services that are available

Acknowledgements



Name	Position/Organization
Tele Hill	Facilitator/ Department of Health
Fa'asegi Caldwell	Member/ Cancer Survivor
Joan Galeai-Holland	Member/ Cancer Survivor
Evalani Pearson	Member/ Cancer Survivor
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Taeaoafua Meki Solomona	Member/ Starkist Cannery
Va'a Tofaeono	Member/ Cancer Coordinator



Demographics of American Samoa

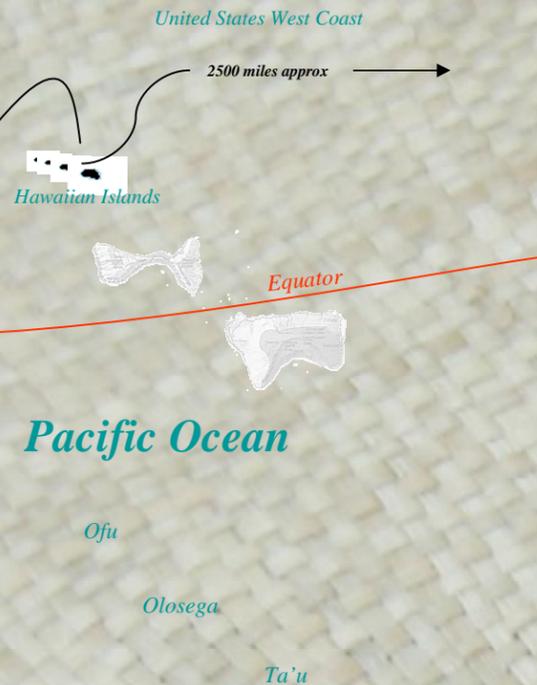
- The only U.S. territory located below the equator.
- Situated in the heart of the South Pacific.
- *American Samoans* represent the largest group of Polynesian people.
- The culture has lasted for over 2000 years.
- The Pago Pago harbor, is one of the best natural deepwater harbors in the South Pacific Ocean.

American Samoa Islands

Comprised of 7 Individual Islands:

Tutuila
Ofu
Olosega
Ta'u

Not Shown:
Rose Island
Swains Island



Total Population = 52,791 residents

<u>Ethnicity</u>	<u>%</u>
Pacific Islander	92.9
Asians	2.9
Caucasian	1.2
Mixed	2.8
Other	0.2

Approx 97% reside on Tutuila

** 2000 U.S. Census **

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CANCER REGISTRY

Sections:

13.0401 Establishment

13.0402 Cancer registry data and confidentiality

13.0403 Promulgation of rules

13.0401 Establishment.

A population-based, territory-wide cancer registry is hereby established. The Department of Health shall administer and maintain the cancer registry established under this section.

History: 1998, PL 25-22.

13.0402 Cancer registry data and confidentiality.

The Department of Health shall collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), data concerning:

- (1) demographic information about each case of cancer;
- (2) information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;
- (3) administrative information, including date of diagnosis and source of information;
- (4) pathological data characterizing the cancer, including the cancer site, stage of disease, incidence, and type treatment; and
- (5) other elements determined by the Department of Health.

All data collected under this section shall be considered confidential as to the names of persons or physicians concerned, except that researchers may use the names of such persons when requesting additional information for research studies when such studies have been approved by the Director of Health.

History: 1998, PL 25-22.

13.0403 Promulgation of rules.

The Department of Health shall develop rules necessary to:

- (1) ensure complete reporting by hospitals, laboratories, physicians and other health care practitioners diagnosing, or providing treatment for cancer patients;
- (2) ensure access to all records that would identify cases of cancer or establish characteristics of the cancer, treatment of the cancer, or medical status of the individual patient;
- (3) protect the confidentiality of all cancer data reported to the registry;
- (4) establish the format, quality requirements, completeness, and timeliness of required data;
- (5) and protect individuals complying with the law including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the cancer registry."

We must be of one mind in the undertaking



6.1C

By year four, advocate to the Fono to amend the current legislation to require those who are responsible for disseminating cancer data obtain a certification as a CTR.

All activities and projects that are developed and/or implemented in regards to patient cancer data will be approved first by the LBJ Compliance Office assuring HIPAA requirements are met.

6.1D

In year one, staff from ASCCC, LBJ, and DOH, will assess available software that can maximize cancer data collection and streamline results to all programs (e.g. Abstract Plus).

6.3B

All employees of ASCCC, DOH, and LBJ must attend required HIPAA training offered at LBJ.

6.1E

By year 4, develop a plan strategically designed to move at least 75% of all current medical records from paper to electronic.

6.3C

In year 3, staff of ASCCC, LBJ, and DOH will standardize the collection and categorization the cancer data for each organization.

Objective 6.4

Establish the format, quality requirements, completeness, and timeliness of required data.

Objective 6.2

Ensure access to all records that would identify cases of cancer or establish characteristics of the cancer, treatment of the cancer, or medical status of the individual patient.

Strategies

Strategies

6.2A

By year 2, integrate the chosen software into the current Vista medical software that is in currently in place at both LBJ and DOH.

6.4A

In year 2, staff from ASCCC, LBJ, and DOH will use the determined cancer data software (e.g. Abstract Plus) to develop a format that will be used in the VISTA Medical Software that will help abstract cancer data easily.

Objective 6.3

Protect the confidentiality of all cancer data reported to the registry.

6.4B

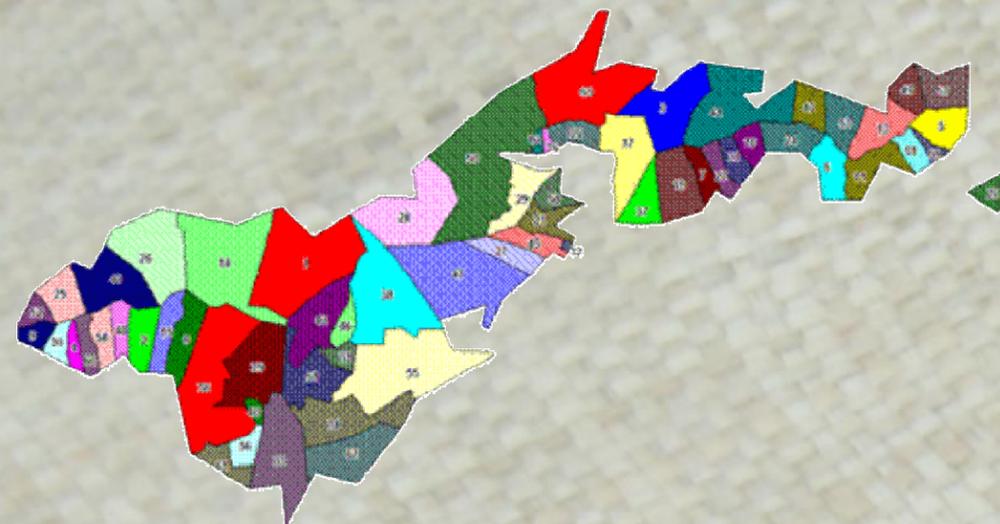
In year 3, the two members that obtain a certification as a CTR will maintain membership in the National Association of Cancer Registrars, attend yearly conferences and enroll in continuing education requirements.

Strategies

6.3A

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Village Infrastructure Island of Tutuila



- | | | | |
|------------|----------------|---------------------------|-----------------|
| 1. Aasu | 18. Auasi | 35. Leloaloa | 51. Pava'ia'i |
| 2. Afao | 19. Aumi | 36. Leone | 52. Poloa |
| 3. Afono | 20. Aunu'u | 37. Lauli'i | 53. Sa'ilele |
| 4. Agugulu | 21. Auto | 38. Malaeimi | 54. Se'etaga |
| 5. Alao | 22. Avaio | 39. Malaeloa/
Aitulagi | 55. Tafuna |
| 6. Alofau | 23. Faga'alu | 40. Malaeloa/Ituau | 56. Taputimu |
| 7. Alega | 24. Faga'itua | 41. Maloata | 57. Tula |
| 8. Amaluia | 25. Fagali'i | 42. Mapusagafou | 58. Utulei |
| 9. Amanave | 26. Fagamalo | 43. Masausi | 59. Utumea East |
| 10. Amaua | 27. Faganeanea | 44. Masefau | 60. Utumea West |
| 11. Amouli | 28. Fagasa | 45. Matu'u | 61. Vailoatai |
| 12. Anua | 29. Fagatogo | 46. Mesepa | 62. Vaitogi |
| 13. Aoa | 30. Failolo | 47. Nu'uuli | 63. Vatia |
| 14. Aoloau | 31. Faleniu | 48. Nua | |
| 15. Asili | 32. Fatumafuti | 49. Onenoa | |
| 16. Atu'u | 33. Futiga | 50. Pago Pago | |
| 17. Aua | 34. Ili'ili | | |

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Background of American Samoa

Political Infrastructure

The Federal Level

The association with the United States began in April 17th, 1900 when Deeds of Cession were signed by the United States and the leading chiefs and orators of the islands of Tutuila and Aunu'u. Following in June of 1904, the Manu'a island group agreed to cede its authority to the United States. American Samoa has a unique relationship to the United States. Its political status remains as an unorganized, unincorporated territory of the United States. The country is "unincorporated" in that not all provisions of the U.S. Constitution apply. As well American Samoa is considered an "unorganic" territory because Congress has not provided the territory with an organic act, which would provide for the organization of the government and its relationship to the federal government. Thus, American Samoans are nationals of the United States and do not vote in federal elections. The islands remained under naval administration from 1900 to 1951, when the President of the United States, with executive order 10264, transferred the administration of American Samoa from the Secretary of the Navy to the Secretary of the Interior.

Territorial Level

Under the terms of the deeds of cession, the United States agreed that the chiefs of the villages would be permitted to retain their individual control over their separate villages, provided such control was in accordance with the laws of the United States pertaining to Samoa and provided that such control was not obstructive to the peace of the people and the advancement of civilization. The United States also agreed to respect and protect the individual rights of the people, especially in respect to their lands and property.

Political Leadership

After World War II, the U.S. Department of Interior sponsored an attempt to incorporate American Samoa with Organic Act 4500. However, the incorporation was defeated in the U.S. Congress primarily through the efforts of American Samoan chiefs. These chiefs' efforts

led to the creation of a local legislature, the **American Samoa Fono** which meets in the village of **Fagatogo**. The **Fono** is modeled after the U.S. Congress and has an upper and lower house. The upper house is comprised of eighteen senators, who are elected by court councils in accordance with traditional Samoan customs. The lower house is made up of 20 representatives who are popularly elected.

In 1977, the appointee process of governor was replaced by a locally elected Governor and Lieutenant Governor and in 1981, American Samoa sent its first non-voting delegate to the U.S. congress.

Economy

American Samoa has a traditional Polynesian economy in which more than 90% of the land is communally owned. Economic activity is strongly linked to the US with which American Samoa conducts most of its foreign trade. Tuna fishing and tuna processing plants are the backbone of the private sector, with canned tuna as the primary export. Transfers from the US Government add substantially to American Samoa's economic well being. Attempts by the government to develop a larger and broader economy are restrained by Samoa's remote location, its limited transportation, and its devastating hurricanes. Tourism is a promising developing sector. The Gross Domestic Product (GDP) based on 2000 estimate is at \$500 million with per capita at \$5,800 (2000 est). Labor force is at 30,200 (1996) with 34% on agriculture, 33% on industry and 33% on services. Unemployment rate is at 29.8% (2000). The country's revenue of 37% comes from local sources (tuna cannery, agriculture, handicrafts) and 63% are from U.S. grants. It is estimated that 67% of families fall below the Federal poverty level (2000).

Cultural Aspects of American Samoa

Fa'a Samoa, means the Samoan Way. This is an all encompassing concept that dictates how Samoans are meant to behave. It refers to the obligations that a Samoan owes their family, community and church and the individuals sense of Samoan identity. The concept of respect is also very important. You must always respect your betters, this includes those older than you, matais or chiefs of the villages, ministers, politicians, doctors and teachers. This unquestioning demand for respect is taking its toll in modern



ensure access to all records that would identify cases of cancer or establish characteristics of the cancer, treatment of the cancer, or medical status of the individual patient;

protect the confidentiality of all cancer data reported to the registry;

establish the format, quality requirements, completeness, and timeliness of required data;

protect individuals complying with the law including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the cancer registry."

In reviewing some of the databases available, it was found that there was no uniformed software system being used in the gathering or dissemination of cancer data. One program used a Microsoft Access database file to compile data, while another program used hand written log books that were to be compiled in an Excel Spreadsheet. These log books were also examined and found that most of the information was unreadable. Also after reviewing and comparing data from the log books and the database located at the Breast and Cervical Cancer Early Detection Program (BCCEDP), there was more breast cancer cases reported in one month, according to the log books, then were reported in the same year to the BCCEDP database.

Improving the Collection and Quality of Data in American Samoa

During the initial CCC planning phase, the ASCCC developed a work group that was specifically designed to offer solutions to improving the collection and quality of data

in American Samoa. Members of this group included the data collection manager for the BCCEDP, the quality compliance officer from LBJ Tropical Medical Center, the manager of the Management of Information Services department of LBJ Tropical Medical Center and other community members. It was decided upon that re-establishing the requirements set forth by the local legislation and with guidelines provided by the American Cancer Society's Commission on Cancer would be the best course of action. Therefore, there are four main objectives that will be addressed in the first five years of implementation of the CCC plan: proper reporting, access, confidentiality, and quality. The following strategies will be used accomplish our goals.

Objective 6.1

Ensure complete reporting by hospitals, laboratories, physicians and other health care practitioners diagnosing, or providing treatment for cancer patients.

Strategy

6.1A

In year one, staff from ASCCC, LBJ, and DOH will enter into a Memorandum of Agreement with the Pacific Association for Clinical Training to develop a CME curriculum based upon ICD-10, or equivalent, and CPT coding.

6.1B

By year one, select two members (possibly one from LBJ and one from DOH) to attend online training to receive certification as a Certified Tumor Registrar (CTR).



Data Collection Goals and Objectives

Improve and maintain a high quality data collection system assuring correct decision making.

For American Samoans, cancer is and becoming a greater concern for our population. Cancer was the second leading cause of death from 1998-2001. Reducing our cancer burden is a great task that involves many people, including health professionals, researchers, epidemiologists, community members, and others. All of these people appreciate and rely on cancer data in our efforts to eliminate cancer in our territory.

Physicians need cancer data to learn more about the causes of cancer and detect cancer earlier, thereby increasing the chance of finding a cure and prolonging the life of the patient. Oncologists make treatment choices based on accurate cancer data from pathology reports.

Cancer data may even point to environmental or behavioral risk factors (including, but limited to: high levels of radiation, tobacco use, diet) that help to take preventative measures that are more effective in our territory.

Cancer Data in American Samoa

Currently, there is legislation that allows for a Territorial Cancer Registry to be housed at the local Department of Health. American Samoa Public Law # _____ states:

The Department of Health shall collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), data concerning:

(1) demographic information about each case of cancer;

(2) information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;

(3) administrative information, including date of diagnosis and source of information;

(4) pathological data characterizing the cancer, including the cancer site, stage of disease, incidence, and type treatment; and

(5) other elements determined by the Department of Health.

However, there have been some barriers in establishing an official cancer registry due to lack of funding and resources (e.g. personnel, training, dedicated equipment). This did not stop some programs, both from Department of Health and LBJ Tropical Medical Center, from collecting limited cancer data on patients that attended outreach clinics or other preventative screening activities. These individual programs established and maintained their own databases that collected cancer data pertinent to their respective objectives. These databases are maintained at the following locations:

Department of Health, Breast and Cervical Cancer Early Detection Program
 Department of Health, Health Information Office
 LBJ Tropical Medical Center, Laboratory
 American Samoa Government, Vital Statistics.

Quality of Data

Within the local legislation, it is clearly stated that the Department of Health shall develop rules pertaining to all cancer data that is collected:

“ensure complete reporting by hospitals, laboratories, physicians and other health care practitioners diagnosing, or providing treatment for cancer patients;



Samoa as the younger generation constantly finds itself trying to balance the demands of a conservative Samoan society with its knowledge of the world, increasingly gathered from overseas education and experience. This has led to one of the highest suicide rates in the world. There is also an evident in the legal system which is actually two separate systems, a western style system administered by a police force and justice department, and a traditional system administered at a village level. The two systems do occasionally come into conflict with one another but generally things work smoothly.

The American Samoans have a strong Christian community which dates back to the days of Reverend Williams who came to the islands in the 1830s representing the American Board of Commissioners for Foreign Missions. He was soon convinced that the natives to turn their backs on their traditional gods and to turn to the Christian faith. Soon after the L.M.S. arrived, traditional dances were banned and were replaced by religious dance competitions and religious dances. The white church was built on the second Sunday of each October, and celebrated as big as Christmas. All the children of the island received new clothes and special gifts. The church was built around the children. They found up all the duties and run the church from cooking in the early morning hours to conducting services and singing in angel choirs in the churches. Services are conducted and songs sung in Samoan, a dialect similar to other Polynesian languages in the South Pacific.

Some of the other demographic characteristics, such as educational attainment of the population show that of the 25,000 residents 17 years and over, 12.3% attained less than high school education, 21.6% were educated to the 9th grade, 34.1% with no diploma, 39.3% were high school graduates, 12.5% had some college with no degree, 6.9% had an associate degree, 4.8% had a bachelor's degree, and 2.6% had a graduate or professional degree (U.S. Census Bureau, 2000).

Language

The data for language spoken in the home revealed that of the population 5 years and older, that 2.9% use English only whereas 97.1% speak a language other than English; and of these 3.8% speak the other language less frequently than English, 15.3% equally as often as with English, 75.0% more frequently than English, and 3.-% speak no English as at all. Of the other languages used in the homes, 90.6% speak Samoan, 2.4% Tongan, 2.1% other Pacific Island language, and 1.6% other Asian language (U.S. Census Bureau, 2000).



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Health Infrastructure in American Samoa

The health care system in American Samoa practices socialized medicine. According to American Samoa Public Law 13.0602 *Persons are entitled to free medical attention.* The reasons for this law may best be explained by Margaret Mead “*they are... always ready, and obligated by custom to aid.*” (Mead, 1928). It is that custom that leads people to help each other. It is the custom that recognizes the strength of the community is based on the ability of all to access health care.

LBJ relies heavily on subsidies from the American Samoa Government, Department of Interior, and Medicare and Medicaid funding. It also generates funds from collecting user fees before and after patients receive services. However with the rise in medical costs, reductions in subsidies from ASG, and the incapability of patients to pay for services, the same law which provides relief to the residents becomes a burden in the provision of care to the only hospital.

Lyndon Baines Johnson (LBJ) Tropical Medical Center

The LBJ Tropical Medical Center was established in 1968 in honor of U.S. President Lyndon B. Johnson, and is the only hospital facility in the territory. Centrally located in the village of *Faga’alu* on the island of *Tutuila*, the facility functions as a semi-autonomous authority, governed by a five-member board that is selected by the Governor of American Samoa. LBJ serves all residents, as well as visitors to the Territory in following capacity:

- All in-patient and most outpatient services (medicine, surgery, dentistry, and obstetrics/gynecology).
- Emergency room.
- 150 patient beds for general medical services.
- Laboratory services.
- Radiological services (X-ray, CT scan, Mammogram, and Ultrasound)



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When a newly diagnosed cancer patient hears stories like these in American Samoa, it begins to affect their psychological aspect of their lives. Again, feelings of death overcome their thoughts and their self-esteem becomes deeply impacted. If the patient seeks off-island treatment, such as chemotherapy and/or radiation therapy, depression may have already set in and could affect the overall outcome of their treatment. According to the National Institute of Mental Health, “Treatment for depression can help people feel better and cope better with the cancer treatment process².” McDaniel, et al. believes that treatment for depression in a patient with cancer not only improves their quality of life, but also increases their survival time³.

Currently, there are support services that are able to assist cancer patients with some of the issues after diagnosis. In May of 2006, the American Samoa Community Cancer Coalition (ASCCC) established a Cancer Survivor’s Support Group (CSSG) to assist newly diagnosed cancer patients to navigate through the health system. Also, the ASCCC began to fund-raise to help cancer patients with the financial burden by providing stipends that can be used for medication, travel expenses, or however the patient wishes to use it. There are also social service workers, dietitians, religious leaders, physicians, etc, that are able to form an interdisciplinary team that is comprehensive towards palliative care, but there is a lack of coordination and organization between all respective fields.

Objective 4.1
By 2011, increase the capacity of quality of life services that are available on island.

Strategy 4.1a
Maintain and support the current Cancer Survivor’s Support Group (CSSG) on island.

Strategy 4.1b

Assure that programs and services approach cancer as a chronic disease, rather than an acute disease.

Strategy 4.1c
Educate health care providers regarding the available quality of life services available on island.

Strategy 4.1d
Educate patients regarding the available quality of life services available on island.

Strategy 4.1e
Conduct a feasibility study pertaining to the establishment of a comprehensive cancer team/patient navigator.

Objective 4.2
By 2011, increase the accessibility to the quality of life services that are available on island.

Strategy 4.2a
Establish a central point that will house information regarding quality of life services on island.

Strategy 4.2b
Coordinate a mass media campaign focusing on quality of life services (financial, emotional, and physical support) for newly diagnosed cancer patients.

Strategy 4.3a
By 2011, lessen the financial burden on cancer patients and/or family members by obtaining funding from off-island resources specializing in quality of life issues.

References:
http://www.cancer.gov/dictionary/db_alpha.aspx?cdrid=45417
http://www.livestrong.org/site/c.jvKZLbMRIsG/b.1507455/k.5F41/Detailed_Information.htm
http://www.cancer.gov/Templates/db_alpha.aspx?

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teams may be expanded to include a range of professionals, based on the services needed. They include a core group of professionals from medicine, nursing, and social work, and may include some combination of volunteer coordinators, bereavement coordinators, chaplains, psychologists, pharmacists, nursing assistant and home attendants, dietitians, physical-, occupational-, art-, play-, music- and child life therapists, case managers and trained volunteers.”

“Skill in care of the dying and the bereaved: Palliative care specialist teams must be knowledgeable about prognostication, signs and symptoms of imminent death, and the associated care and support needs of patients and their families before and after the death, including age-specific physical and psychological syndromes, opportunities for growth, normal and aberrant grief, and bereavement processes.”

“Equitable access: Palliative care teams should work toward equitable access to palliative care across all ages and patient populations, all diagnostic categories, all health care settings including rural communities, and regardless of race, ethnicity, sexual preference or ability to pay.”

“Quality improvement: Palliative care services should be committed to the pursuit of excellence and high quality of care. Determination of quality requires regular and systematic evaluation of the processes of care and measurement of outcomes data using validated instruments. These aims are built around the core need for palliative care to incorporate attention at all times to safety and systems of care the reduce error, and to be:

- Timely – delivered to the right patient at the right time.
- Patient-centered – based on the goals and preferences of the patient and the family.
- Beneficial and/or effective – demon-

strably influencing important patient outcomes or processes of care linked to desirable outcomes.

Accessible and equitable – available to all who are in need and who could benefit.

Knowledge – and evidence-based. Efficient and designed to meet the actual needs of the patient and not wasteful of resources.”

Although the guidelines that were developed focused more on specialists that dealt with palliative care, it was agreed upon that most palliative care needed to be delivered in a primary treatment setting in the course of routine care.



Quality of Life in American Samoa

In American Samoa, cancer treatment services are very limited. Most patients are referred off-island to Hawaii for services such as chemotherapy and/or radiation, and in most cases when they are referred off-island the diagnosis could be in either stage 3 or 4. Once some patients realize that the cancer they are diagnosed with is terminal, patients only wish to return back to American Samoa and live the last months, maybe days of their lives. Some of the other patients can not even afford to be referred off-island for treatment and either seek the *Fofo*, or traditional healers, or they do not seek help locally and believe that their life is about to end, no matter what stage they are currently in.

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American Samoa Government Department of Health

Centrally located in the village of *Faga’alu* on the island of *Tutuila*, the Department of Health (DOH) is under the umbrella of the American Samoa Government. In order to carry out its purposes, the Department of Health performs the following essential functions:

- Monitors health status to identify community health problems.
- Diagnoses and investigates health problems and health hazards in the community.
- Informs, educates, and empowers people about health issues.
- Mobilizes community partnerships to identify and solve health problems.
- Develops policies and plans that support individual and community health efforts.
- Enforces laws and regulations that protect health and ensure safety.
- Links people to needed personal health services and provides essential community-based primary health care when otherwise unavailable, or inappropriate.
- Assures a competent public health and personal health care of the workforce.
- Evaluates effectiveness, accessibility, and quality of personal and population-based health services.
- Researches for new insights and innovative solutions to health problems.



As the Lyndon Baines Johnson Tropical Medical Center (LBJTMC) handles medical services for the entire territory, DOH is primarily responsible for all preventative services. Some of the public health services include:

- Health Education
- Family Planning
- HIV Prevention
- Maternal and Child Health
- Immunization
- Nutrition
- Chronic Disease Management
- Breast and Cervical Cancer Early Detection Program
- Tobacco Prevention and Control

Currently, residents can receive services at 5 community-based primary care clinics throughout the islands.



Faga’alu



Va’asa Amoa performing education and outreach in Manu’a

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American Samoa Community Cancer Coalition (ASCCC)

The ASCCC began in June of 2004 with the task of developing a Comprehensive Cancer Control Plan. Since then, it has developed into a Non-Governmental Organization that is community based with a mission to: “coordinate cancer education, prevention, early detection, treatment, support, and research efforts to improve the quality of life for American Samoa’s residents.” The goals for the ASCCC are:

- Promote the collection and use of information to increase professional and public understanding and education about cancer and its impact on American Samoa’s residents.
- Encourage and promotion of American Samoa residents as a step towards preventing cancer.
- Increase the percentage of American Samoa residents who appropriately access and utilize screening services to diagnose cancer at its earliest stages.
- Increase the percentage of American Samoa residents who have access to state-of-the-art cancer diagnosis, treatment, follow-up, rehabilitation, and palliative care services.
- Increase the support of policies that enable cancer prevention and control to improve the health and environment on American Samoa.
- Warrant programs and activities to eliminate disparities in cancer incidence and mortality in American Samoa due to gender, ethnicity, race, socioeconomic status, insurance status, place of residence, or age.

Currently the ASCCC has expanded to aid cancer patients financially through local fundraising events, established a Cancer Survivor’s Support Group, and with the establishment of a federal tax exempt status (501c3) more funds towards cancer can now be leveraged. The ASCCC is governed by a seven member board that is selected by the general membership on a yearly basis and general membership meetings are held every two months and announced by the local media.



Quality of Life Goals and Objectives



Improve the ability for patients to enjoy a normal life while receiving cancer treatment.

The National Cancer Institute defines **Quality of Life** as:

“The overall enjoyment of life. Many clinical trials assess the effects of cancer and its treatment on the quality of life. These studies measure aspects of an individual’s sense of well-being and ability to carry out various activities.”¹

Quality of life can also be referred to as **Palliative (PAL-yah-tiv) Care**. According to the Lance Armstrong Foundation (LAF) palliative care is any type of care that is meant to relieve the symptoms or problems caused by cancer or other diseases. Although this type of care was once more commonly associated with end of life, the goal of palliative care is to relieve physical, emotional and practical concerns at all stages of illness².

Normally when a patient is diagnosed with cancer, feelings of death, interruption of life plans, changes in body image and self-esteem, changes in social role, lifestyle, and medical bills are important issues to be faced³. Quality of life services are focused on assisting diagnosed patients through these challenges, improving the overall patient’s ability to enjoy normal life activities while at any stage of survivorship/ treatment.

Quality of Life Nationally

The National Consensus Project for Quality Palliative Care was established as a result to the rise of palliative care services outside hospices with populations living with debilitating and life limiting illnesses. The National Consensus Project for Quality Palliative Care developed a mission to “create a set of clinical practice guidelines to improve the quality of palliative care in the United States.” The specific aim of the

mission was focused on promotion of quality and to reduce variation in new and existing programs, develop and encourage continuity of care across settings, and facilitate collaborative partnerships among palliative care programs, community hospices and a wide range of other health care delivery settings. In order to accomplish this, a national professional consensus was established on what constitutes high-quality palliative care. As a result, the National Consensus Project agreed on key elements of palliative care. Key elements included⁴:

“**Timing of palliative care:** Palliative care ideally begins at the time of diagnosis of a life-threatening or debilitating condition and continues through cure, or until death, and into the family’s bereavement period.”

“**Comprehensive care:** Palliative care employs multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social and spiritual distress. Care providers should regularly assist patient and their families to understand changes in condition and the implications of these changes as they relate to ongoing and future care and goals of treatment. Palliative care requires the regular and formal clinical process of patient-appropriate assessment, diagnosis, planning, interventions, monitoring and follow-up.”

“**Interdisciplinary team:** Palliative care pre-

“There is life after cancer”¹

**Lora Taylor-Falealili
Breast Cancer Survivor**

supposes indications for, and provision of, interdisciplinary team evaluation and treatment in selected cases. The palliative care team must be skilled in care of the patient population to be served. Palliative care



local oncology center, lack of oncologists or hematologists, interventions such as radiation, chemotherapy, and targeted therapy are provided off-island for the duration of their treatment and follow-up. However, LBJ TMC has the capacity to provide maintenance chemotherapy and hormonal therapy, usually started at Honolulu medical facilities. All patients requiring radiation and chemotherapy are referred off-island for the duration of their treatment and follow-up. However, LBJ TMC has the capacity to provide maintenance chemotherapy, usually started at Honolulu medical facilities.

With the lack of health insurance or inadequate coverage, the difficulty in getting to services, fear of losing everything, and the cultural belief systems influence decisions individuals make regarding cancer treatment and care.

Objective 3.1
By 2011 decrease the amount of time a patient spends between diagnosis and treatment.

- Strategy 3.1a
Create a coordinated and central point of information housing on and off island resources relating to cancer treatment.
- Strategy 3.1b
Increase healthcare providers' knowledge of on and off island resources relating to cancer treatment.
- Strategy 3.1c
Establish a territorial wide standard for cancer care and lobby for that standard to become legislation.
- Strategy 3.1d
Develop an off-island infrastructure based in Honolulu for off-island cancer referrals.
- Strategy 3.1e
Maintain ASCCC fundraising activities aiding in financial assistance for newly diagnosed cancer patients.

Strategy 3.1f
Include social workers with linkages to support groups and additional resources for cancer treatment.

Objective 3.2
By 2011, increase healthcare capacity regarding cancer treatment on island.

- Strategy 3.2a
Provide training, preferably through video teleconferencing (VTC), for health professionals in interpreting/reading CT films, mammograms, etc.
- Strategy 3.2b
Increase the number of nurses trained in chemotherapy treatment given on island.
- Strategy 3.2c
Develop Memorandum of Understanding (MOU)/ Memorandum of Agreement (MOA) with the Pacific Association of Clinical Training (PACT) specifically for developing a curriculum training healthcare providers on best practices of cancer care for each site.

Objective 3.3
Increase the laboratory capacity in regards to diagnosing cancer.

- Strategy 3.3a
Locate funds that aid in obtaining equipment, supplies and reagents.
- Strategy 3.3b
Conduct a feasibility study for the possibility of hiring a pathologist specializing in Histochemistry.

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American Samoa Breast and Cervical Cancer Early Detection Program

The American Samoa Breast and Cervical Cancer Early Detection Program (ASBCCEDP) is currently located at the Department of Health in the village of Faga'alu and is funded by the Centers for Disease and Control's National Breast and Cervical Cancer Early Detection Program. The program was established in 1994 and has two main objectives:

- Reduce breast and cervical cancer morbidity and mortality through early detection of cancer by screening.
- Provide comprehensive breast and cervical cancer screening services for all women who are unable to afford them.



Nurse Practitioners (Left to Right)
Margaret Sesepasara, Tele Hill



ASBCCEDP Staff: (Left to Right) Data Manager Drusilla Vaoalii, Health Educator Va'asa Amoa, Program Coordinator Moira Wright, Admin. Assistant Maryann Schwenke

In order to achieve these objectives the program began with a local motto of "E Taua Tama'ita'i Uma" which translates to "Every Woman Matters". The program also performs screening services (pap smears, pelvic examinations, clinical breast examination, mammography for women age 50 and above), public education and awareness activities (risk factors, signs and symptoms, benefits of early detection), and counseling. The ASBCCEDP offers these services until a patient is diagnosed as benign or malignant with the aid of program staff and two contracted nurse practitioners at the LBJ Tropical Medical Center OB/GYN clinic on Tuesdays and Thursdays, and at the Tafuna Family Health Center on Thursdays. Also, outreach and awareness programs are provided to villages and outlying islands. If there are any abnormal or suspicious findings, patients are to be referred to LBJ TMC.

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American Samoa Community Cancer Network

The ASCCN is a 5 year project (2005-2010) funded by the National Cancer Institute's Centers to Reduce Cancer Health Disparities division and is a collaborative effort between the Lyndon Baines Johnson Tropical Medical Center (LBJ TMC), American Samoa Department of Health (ASDOH), and the American Samoa Community College. The Network has established partnerships with on and off island resources including: American Samoa Community Cancer Coalition, Papa Ola Lokahi, 'Imi Hale, Cancer Information Services Pacific, and others, all of whom provided invaluable technical assistance and support to train researchers, and develop organizational infrastructure.

The main goal of ASCCN is to: "reduce the incidence of cancer in American Samoa through research, education, project development and outreach."



Victor Tofaeono, MD, FACS
Principal Investigator

In order to achieve its goal, the network focuses on five main objectives:

- Establish the ASCCN infrastructure using Memorandum of Agreements (MOA) with partnering agencies and convening and staffing the Steering and Community Advisory Committee.
- Foster and facilitate the development and implementation of cancer education programs to increase cancer awareness among American Samoans.
- Create programs and opportunities to identify and develop indigenous researchers through training of promising young students, graduates, health care providers and physicians.
- Develop programs to increase the number of research grants addressing cancer in American Samoa.
- Establish a culturally appropriate participatory research process that is respectful of American Samoan cultural beliefs, practices and customs.



ASCCN Research Trainees

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body cavity, or delivered orally in the form of a pill. Chemotherapy is different from surgery or radiation therapy in that the cancer-fighting drugs circulate in the blood to parts of the body where the cancer may have spread and can kill or eliminate cancer cells at sites great distances from the original cancer. As a result, chemotherapy is considered a systemic treatment.

More than half of all people diagnosed with cancer receive chemotherapy. For millions of people who have cancers that respond well to chemotherapy, this approach helps treat their cancer effectively, enabling them to enjoy full, productive lives. Furthermore, many side effects once associated with chemotherapy are now easily prevented or controlled, allowing many people to work, travel, and participate in many of their other normal activities while receiving chemotherapy.

Hormonal Therapy

Hormones are naturally occurring substances in the body that stimulate the growth of hormone sensitive tissues, such as the breast or prostate gland. When cancer arises in breast, or prostate tissue, its growth and spread may be caused by the body's own hormones. Therefore, drugs that block hormone production or change the way hormones work, and/or removal of organs that secrete hormones, such as the ovaries or testicles, are ways of fighting cancer. Hormone therapy, similar to chemotherapy, is a systemic treatment in that it may affect cancer cells throughout the body.

Targeted Therapies

A targeted therapy is one that is designed to treat only the cancer cells and minimize damage to normal, health cells. Cancer treatments that "target" cancer cells may offer the advantage of reduced treatment-related side effects and improved outcomes.

It is important to understand that surgery is only capable of treating the cancer cells that are removed during surgery and can not treat cells that have already spread through the blood and lymph system to other locations in the body. These cancer cells are referred to as **micrometastases** and currently available tests cannot always detect micrometastases. Information obtained during surgery and from other tests determines the likelihood of the cancer having spread and whether additional treatment with chemotherapy, radiation, or hormonal therapy is necessary.

Cancer treatment varies depending upon your type of cancer, stage of cancer, and overall condition. Additionally, your treatment may vary depending on whether or not the goal of your treatment is to cure your cancer, keep your cancer from spreading, or to relieve the symptoms caused by cancer. Depending on these factors, you may receive one or more the following:

Cancer Diagnosis in American Samoa

Services related to cancer diagnosis are provided by surgeons, gynecologists, and the acting Chief Medical Officer, a member of a national professional society for practitioners specializing in breast cancer, the American Breast Society at the Lyndon Baines Johnson Tropical Medical Center (LBJ TMC). Diagnostic services include colposcopy and biopsies of the breast, lymph nodes, skin, colon, prostate and thyroid. Once a biopsy is performed, it is reviewed in the pathology laboratory at LBJ TMC and then sent off island to Honolulu for verification.

Cancer Treatment in American Samoa

Treatment services available on island are also performed at the LBJ TMC and are limited to some surgical interventions (Lumpectomy, Mastectomies,). Surgical treatments involving almost all cancer sites are referred off island, mostly at the cost of the patient. Without the availability of a

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Diagnosis/Treatment Goals and Objectives

As soon as cancer is detected, assure that the most current and available treatments are used.

Diagnosis: A process of identifying a disease by the signs and symptoms.

In order to properly diagnose a cancer, a physician will typically perform a **biopsy (BY-op-see)** of a suspicious area, lump or mass suspected of being cancer. A biopsy can be performed on an outpatient basis and normally involves the physician to remove cells or tissues from the suspicious area, lump, or mass. There are three main criteria that distinguish the type of biopsy that would be performed:

Incisional Biopsy: When only a sample of tissue is removed

Excisional Biopsy: When an entire lump or suspicious area is removed

Needle Biopsy: When a sample of tissue or fluid
Core Biopsy is removed with a needle
Fine Needle Aspiration (FNA)

During a biopsy, part or all of the suspected cancer is removed and cells contained in the sample are sent to a **pathologist** who may study the tissue under a microscope or perform other tests to determine if the cells are **malignant (Cancerous)** or **benign (Non-Cancerous)**. If the biopsy indicates that cancer is present, additional tests to determine the stage of cancer may be performed. Surgery may be performed as part of the staging evaluation and/or as part of treatment after the patient and doctor determine the overall treatment plan.

Treatment: The Administration or application of remedies to a patient or for a disease or injury; medicinal or surgical management; therapy. The success for treatment of cancer often requires the involvement and coordination of several treatment methods. Normally this is referred as **multi-modality treatment** and may include:

- Surgery
- Radiation therapy
- Chemotherapy
- Hormonal therapy
- Targeted therapy

Surgery

Surgery is used to diagnose cancer, determine its stage, and to treat cancer. When surgery is used for treatment, the cancer and some tissue adjacent to the cancer are typically removed. In addition to providing local treatment of the cancer, information gained during surgery is useful in predicting the likelihood of cancer recurrence and whether other treatment modalities will be necessary.

Radiation Therapy

Radiation therapy, or radiotherapy, uses high-energy rays to damage or kill cancer cells by preventing them from growing and dividing. Similar to surgery, radiation therapy is a local treatment used to eliminate or eradicate visible tumors. Radiation therapy is not typically useful in eradicating cancer cells that have already spread to other parts of the body. Radiation therapy may be externally or internally delivered. External radiation delivers high-energy rays directly to the tumor site from a machine outside the body. Internal radiation, or brachytherapy, involves the implantation of a small amount of radioactive material in or near the cancer. Radiation may be used to cure or control cancer, or to ease some of the symptoms caused by cancer. Sometimes radiation is used with other types of cancer treatment, such as chemotherapy and surgery, and sometimes it is used alone.

Chemotherapy

Chemotherapy is any treatment involving the use of drugs to kill cancer cells. Cancer chemotherapy may consist of single drugs or combinations of drugs, and can be administered through a vein, injected into a



American Samoa Tobacco Prevention and Control Program

The American Samoa Tobacco Prevention and Control Program is currently located at the Department of Health in the village of *Faga'alu* and is funded by the Centers for Disease and Control (CDC). The program's goal is to reduce disease, disability, and death related to tobacco use by:

- Preventing the initiation of tobacco use among young people.
- Promoting quitting among young people and adults.
- Eliminating nonsmokers' exposure to environmental tobacco smoke (ETS).
- Identifying and eliminating the disparities related to tobacco use and its effects among different population groups.

Currently, the program also has established a Tobacco Quitline, a Nicotine Replacement Therapy program, and supports local groups interested in stopping the use of tobacco products.





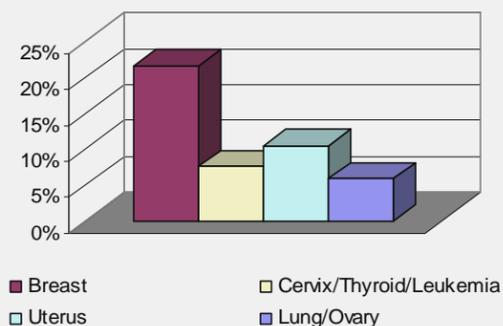
Burden of Cancer in American Samoa

Incidence....

The collection of baseline data related to cancer incidence in American Samoans began with a project assessing cancer data from 1980-1988. This project was carried out by the University of California, Irvine and funded by the National Cancer Institute (NCI) in 1996. At that time, local legislation was not in place in American Samoa making data unreliable and the project to be dependant on gathering information from the Hawaii Tumor Registry from 1980-1988. The tumor registry is a Surveillance, Epidemiology, and End Results (SEER) contract from NCI, is population-based, and collects cancer data on American Samoans living in Hawaii and on those who are referred to Hawaii for diagnostic and treatment services¹. Table 1 reflects the top five cancer sites diagnosed in males and Table 2 reflects the top 7 cancer sites diagnosed in females during 1980-1988¹.

Table 2. Source: Hawaii Tumor Registry

Cancer Diagnosis by Cancer Site Females (1980-1988) N=171



A more recent and on-island assessment came with the aid of the University of Hawaii's Department of Family Practice and Community Medicine at the John A. Burns School of Medicine (JABSOM), and the Cancer Council of the Pacific Islands (CCPI), and was performed by two medical residents and was also funded by NCI in 2003. Results showed that during the years of 2000-2002, 100 cancer cases were diagnosed between both genders and Table 3 reflects the top six². In comparison to 1980-1988, there have been no significant changes

Cancer Diagnosis by Site of Males (1980-1988) N=211

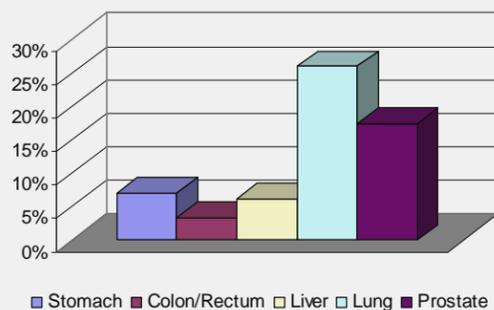


Table 1. Source: Hawaii Tumor Registry

References:

1. Cancer among Indigenous Populations. (Shiraz, et al) June 1996
2. Cancer in American Samoa, Pacific Health Dialog, September 2004. Volume 11. No. 2

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How to overcome these barriers

From this one study it became quite evident that the misinformation, lack of awareness and education of the meaning of cancer and the benefits of early detection needs to be communicated to the public. The participants of this study believed that their family priorities were "health, family, and education." They also believed that their well being in the family helped to stabilize their family infrastructure, thus their own attitudes and beliefs affected the family's attitudes and beliefs towards their own personal health.

The objective here is to reassure our residents that early detection provides better options for treatment and prolonged lives with their families. The following goals and objectives will help us achieve this within the first five years of implementation.

*"Sometimes when the doctors say they have cancer, they feel, 'That's it,' and there's no hope. It is important to have the education, screening, and raise awareness of the community. Everyone is affected, not just that person."*¹

*Mrs. Torise Saifoloi
Cervical Cancer Survivor*



Objective 2.1

By 2012, increase screening rates by 30% focusing on the five primary sites: Breast, Cervix, Prostate, Colon, and Lung.

Strategy 2.1A

Conduct a mass media campaign (e.g. television, radio, brochures, etc.) focusing on the five primary sites.

Strategy 2.1B

Expand current outreach strategies (e.g. Annual Smokeout Day, Mammo-Day, Men's Health Care Clinic for Prostate Cancer with Tobacco Prevention and Control, Breast and Cervical Cancer Early Detection Program, and American Samoa Community Cancer Network and develop outreach activities that include Colon cancer.

Strategy 2.1C

Educate local employers in the understanding of the importance of early detection and screening with their employees.

Strategy 2.1D

Develop a policy that mandates all government employees undergo cancer screening methods according to guidelines that are set forth.

Objective 2.2

By 2012, increase the screening capacity of healthcare providers within the territory.

Strategy 2.2A

Develop a mechanism to determine which organizational screening recommendations should be adopted by LBJ Tropical Medical Center and Department of Health.

Strategy 2.2B

Develop a culturally competency curriculum for healthcare providers around recommended screening guidelines.

Strategy 2.2C

Develop a curriculum for health care providers focusing on the importance and benefits of early detection screening methods.

Objective 2.3

Maintain available screening tools (radiological films, FOBT cards, antigens) in stock for screening activities.)

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that aid in the effectiveness of preventing cancers, and the cultural beliefs of cancer among our residents. The local Breast and Cervical Cancer Early Detection Program (BCCEDP) is the main source of early detection for those respective cancers. However, results taken from patients who are referred to their programs must be delivered to facilities off-island to be analyzed. Currently, mammograms, ultrasounds, and biopsies are performed on island but results are sent to be analyzed by an off-island source. For example, all mammograms are sent to a diagnostic imaging center in Las Vegas, Nevada, and with only two flights per week from our island to Honolulu, delays in receiving results in a timely fashion may occur.

Cultural beliefs

Cultural beliefs regarding cancer is also a disparity that prolongs patients from obtaining the proper screening tests that detect cancers at an earlier stage. Three main purposes for residents to not receive proper early detection screening tests include:

- Causes of Cancer
 - Cultural Appropriateness of screening methods
 - Disbelief in the current medical system
- The following paragraphs explain these three concepts as related to breast cancer only. Current data on other cancers is being researched at this time.

Causes of Cancer

The following is an excerpt from the Beliefs and Attitudes of Samoan Women towards Early Detection of Breast Cancer and Mammogram Utilization. A group of 15 women participants ranging from the age of 40-73 were questioned.

“Seven women mentioned that the causes of cancer are diet and heredity. Women noted that they ate too much processed food, fast food, sodas, sweets, and greasy foods. One woman commented that Samoans had become an obese society and a fried food culture. Concern about frozen food by another respondent

was related to her past experiences. She stated that the food she used to eat was from the land and from the sea and that, at that time, there were no frozen foods. The next frequently believed causes of cancer were trauma and environment (three study participants each). One woman noted that not wearing a bra could cause breast cancer, whereas another noted that if a man hits his wife on her breast, cancer could result. Causes of cancer attributed to the environment included chemicals in the water, the environment, and the air. Other participants listed causes of cancer as lifestyle, infection, stress, smoking, and contagion. The latter response was from a woman caring for her mother who had cancer. She noted, “I didn’t protect myself. I didn’t know if cancer gets transferred to one another.” Participants frequently listed both currently accepted causes and risk factors and less accepted risk factors and causes for breast cancer.”

It was concluded in this report that the participants had strong beliefs that cancer meant “death” and therefore no cure. One participant believed that cancer was an illness that doctors could not find a cure.

Cultural Appropriateness of Screening Methods

During the same study, most of the women commented that some of the screening methods, self breast exam (SBE) and clinical breast exam (CBE), made women feel uncomfortable. One participant commented “You know how anything to do with the breast, the genitals, you know, the naked body seems to have been regarded as taboo.” “It feel[s] funny... [be]cause you never, to me, touch yourself like that,” noted a 47 year old participant. Two of the study participants aged 66 years and 50 years, said that they did not want anyone to touch their breasts.

Disbelief in the current medical system

Some of the participants expressed negative experiences in their relationship to the LBJ Tropical Medical Center in either their own personal or a family member’s experience in not only dealing with cancer



**Cancer Diagnosis by Site
Male and Female (2000-2002)
N=100**

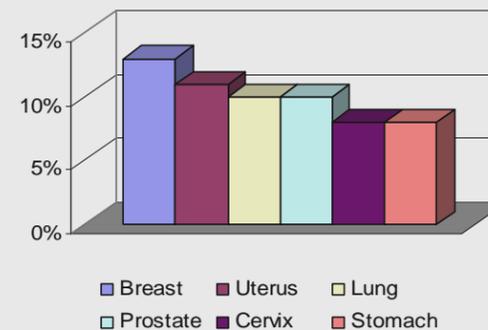


Table 3. Source: LBJ Tropical Medical Center

If a comparison were to be made with this data on an average case per year, based upon the results from these two assessments, a slight increase in the number of cancer cases diagnosed would be realized. For example, breast cancer from 1980-1988 would average to approximately 5 cases per year (37 cases over 8 years). Using data from the 2003 assessment, breast cancer would average approximately 7 cases per year (13 cases over 2 years).

Mortality....

The 2003 assessment also provided baseline data on cancer mortality rates compared to other non-communicable diseases and mortality rates by site. Results showed that cancer was the second leading cause of death on island following heart disease. It was also noticed that the top 6 sites (Table 4) are preventable with behavioral change.

Reality....

In comparing the average case per year data for breast cancer incidence, obtained from the previ-

ous assessments, and data from the American Samoa Breast and Cervical Cancer Early Detection

Program (ASBCCEDP) there is still an increase in breast cancer diagnosis over the past 20 years. Moreover, extrapolating the data and constructing a current trend show that rates will continue to raise.

However, a question still remains if this truly reflects our cancer burden. With the limited data resources available at the time of these assessments, many barriers prevented the accurate reporting of cancer statistics, including:

- Lack of a sustainable cancer registry in the territory.
- Lack of integration between cancer data collection systems on and off island.
- Total number of American Samoans represented in the U.S. census.
- Potential underreporting of cancers due to lack of access to health care, or fear of being diagnosed with cancer.
- Use of traditional healers or *Fofo*'s.

By factoring in these barriers, it becomes obvious that the actual cancer burden is underrepresented and a need for Comprehensive Cancer Control becomes a greater necessity.

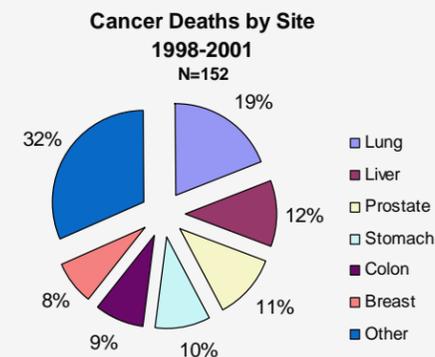


Table 4. Source: Department of Health Health Information Systems

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Health Disparities in American Samoa

Definition of Disparities

The National Cancer Institute (NCI) Centers to Reduce Cancer Health Disparities (CRCHD) defines **disparities** as “inequalities”. These inequalities occur when members of certain population groups do not share the same health status as other groups. Although most disparities are based upon racial and ethnic lines (e.g. African Americans compared to Native Americans), disparities can extend beyond race and ethnicity. For example, disparities can involve socioeconomic status, educational level, disability, gender, age, occupation, sexual orientation and/or geographical location. Populations that suffer from health disparities are more likely to¹:

- Be diagnosed with and die from preventable cancers.
- Be diagnosed with late-stage disease for cancers detectable through screening at an early stage.
- Receive no treatment, or treatment that does not meet accepted standards.
- Die of cancers that are generally survivable.
- Suffer from cancer without the benefit of pain control and other palliative care.

Disparities in American Samoa:

- 67.3% of families are below the federal poverty level (2000 US Census).
- 2000-2002 the top five cancer deaths were²: breast, uterus, lung, prostate, and cervix. These types of cancer are preventable through screening and early detection.

- Lack of proper health professionals to treat and diagnose cancers (e.g. Oncologists, Hematologists, Pathologist specializing in Histochimistry, U.S. certified Radiologist)
- Lack of proper facilities and supplies to treat and diagnose cancers (e.g. chemotherapy and radiation therapies).
- Nearest facilities for proper treatment are located approximately 2,500 miles away in Honolulu, Hawaii. Currently there are only two flights per week provided by Hawaiian Airlines.
- Lack of transportation from villages to preventative and clinical services.
- A healthcare system practicing socialized medicine. (American Samoa Public Law 13.0602)

References:

1. Making Cancer Health Disparities History. U.S. Department of Health and Human Services, March 2004. DHHS Pub. No. 04-5542.
2. Cancer in American Samoa, Pacific Health Dialog, September 2004. Volume 11. No. 2

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Early Detection Goals and Objectives



Detect cancer at its earliest stages when there are no symptoms and treatment leads to a higher cure rate

According to the American Cancer Society, the definition of early detection is to apply a strategy that makes it possible to diagnose cancer earlier. By diagnosing cancer earlier, lives are saved while it is still localized and treatment is more likely to be successful. Normally, prognosis is much better when found early for such prevalent cancers as breast, cervix, colon/rectum, prostate, and lung. In order for cancers to be diagnosed earlier, screening techniques are used to detect the disease. Screening is a means of detecting a disease early in asymptomatic people. For example the National Cancer Institute describes the four stages of breast cancer as:

Stage 0

Carcinoma in situ:

Cancer that involves only the cells in which it began and has not spread to neighboring tissues. Ductal Carcinoma in situ (DCIS) is a very early type of cancer that can spread from the duct into surrounding tissue. Lobular Carcinoma in situ (LCIS) is not cancer, but it indicates an increased risk of developing invasive cancer (cancer that has spread into surrounding tissues). Normally both breasts are infected.

Stage I:

At this stage, cancer is no larger than one centimeter and has not spread outside the breast.

Stage IIA:

At this stage the cancer is either:

no larger than 1 centimeter but has spread to the axillary lymph nodes (lymph nodes under the arm); or between 1 and 2 centimeter but has not spread to the axillary lymph nodes.

Stage IIB:

At this stage the cancer is either:

between 1 and 2 centimeter and has spread to the axillary lymph nodes; or larger than 2 centimeter but has not spread to the axillary lymph nodes.

Stage IIIA:

At this stage the cancer is either: smaller than 2 centimeter, has spread to the axillary lymph nodes, and the lymph nodes are attached to each other or to other structures; or larger than 2 centimeter, has spread to the axillary lymph nodes, and the lymph nodes may be attached to each other or to other structures.

Stage IIIB:

At this stage the cancer has either: spread to tissue near the breast (the skin or chest, including the ribs and muscles); or spread to the lymph nodes inside the chest wall along the breastbone.

Stage IV:

At this stage the cancer has either:

- spread to other organs of the body, most often the bones, lungs, liver, or brain;
- or spread to the lymph nodes in the neck near the collarbone.

If breast cancer is detected earlier by means of a mammogram, clinical breast exam, self breast exam, and/or other methods, by stages 1 or 2, we can reduce the extent of treatment and improve the quality of life for our patients.

Early Detection in American Samoa

In American Samoa, early detection has disparities including : geographic isolation, availability of tests

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routines for residents, educate adolescents (ranging from ages 11-18) on the importance and benefits of physical activity, and developing a mechanism to assess current and future activities that are provided in the territory.

BMI	Category	Waist less than or equal to 40 in. (men) or 35 in. (women)	Waist greater than 40 in. (men) or 35 in. (women)
18.5 or Less	Underweight	N/A	N/A
18.5 - 24.9	Normal	N/A	N/A
25.0 - 29.9	Overweight	Increased Risk	High Risk
30.0 - 34.9	Obese	High Risk	Very High Risk
35.0 - 39.9	Obese	Very High Risk	Very High Risk
40 or Greater	Extremely Obese	Extremely High Risk	Extremely High Risk

Physical Activity

Objective 1.5

Increase the overall physical activity of American

Samoa residents.

- 1.5a Develop a program based upon the “President’s Challenge” to involve local legislative, traditional (chiefs), and/or religious leaders in increasing physical activity in the daily routines of residents.
- 1.5b Educate adolescents (ages 11-18) on the importance and benefits of physical activity.
- 1.5c Develop worksite education materials on the importance of physical activity.
- 1.5d Develop a mechanism based upon the School Health Policies and Program Study (SHPPS) survey to assess school health policies and programs.

<http://www.ptbsd.k12.nj.us/main/Health/obesity.html>

References

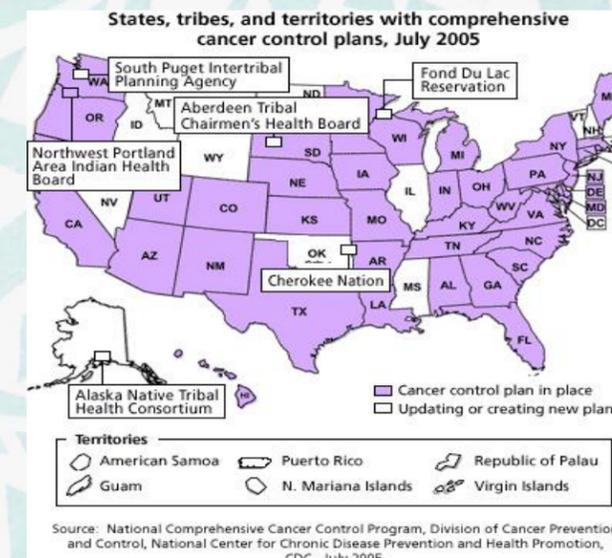
- 7. (<http://www.as.ua.edu/ant/bindon/Food%20and%20Power%20in%20Samoa.pdf>)

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Comprehensive Cancer Control in American Samoa



Table 1



Definition of Comprehensive Cancer Control....

The Centers for Disease and Control define Comprehensive Cancer Control (CCC) as “an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation.” CCC uses a comprehensive, or broad, approach towards cancer control because of the existence of gaps in service delivery and coverage, includes major forms of cancer, all population groups, and all geographic regions. Thus the scope of CCC involves a diverse group of **stakeholders** who must coordinate their efforts. For this reason, the partnership of stakeholders involved in developing a CCC plan should also be broad. Usually coordinated efforts occur in a context of a formal **collaboration** across multiple disciplines and organizations. As of 2005, nearly 80% of the states and one Native American tribe currently have comprehensive cancer control plans. Eleven states, the District of Columbia, four tribes, and six territories are in the process of developing plans (Table 1).

The First Step of Comprehensive Cancer Control in American Samoa....

We recognize that *our* strongest trait is *our* commitment to each other through unity and community service. It may be best explained by Margaret Mead “they are...always ready, and obligated by custom to aid” (Mead, 1928). Together with this and the fundamentals of

CCC, we realized that the best way to achieve our goals was to form a community based organization allowing for a diverse group of stakeholders able to collaborate and implement CCC. As a result, in 2004 we created the American Samoa Community Cancer Coalition (ASCCC).

Development of a Comprehensive Cancer Control Plan....

The ASCCC began the planning process in 2004. Through funding from the Centers for Disease and Control, funding was made available from the University of Hawaii through a regional collaboration with the United States Pacific Island Nations (Federated States of Micronesia, Republic of the Marshall Islands, Commonwealth of the Northern Mariana Islands, Guam and American Samoa) to begin the planning process. Throughout the entire process, technical assistance was provided by the Department of Family Practice and Community Medicine at the John A. Burn School of Medicine, University of Hawaii, Cancer Council of the Pacific Islands, and Papa Ola Lokahi.

The first steps for developing a CCC plan began with deciding upon principles that would guide us in establishing goals and objectives that would be Specific, Measurable, Attainable, Realistic, and have a Timeframe (SMART). Stakeholders from the ASCCC developed these following guidelines:

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All decisions will be made by the best available data. Most data that was used was ascertained by a cancer needs assessment completed in 2004.

Although most objectives are to improve or develop cancer programs or systems, an assessment of these programs or systems must be completed first. These were to be reflected in the action steps of each individual goal.

Coordination and collaboration is pivotal in the completion of a comprehensive cancer control plan. At some time, every resident in American Samoa will be touched by cancer. This makes the responsibility of cancer control for everyone in American Samoa – its



institutions, organizations, individual citizens, families, businesses and communities.

When available, state-of-the-art knowledge, technology, and practices will be the foundation for all strategies and actions the plan promotes.

Equal access to cancer services must be available to all residents. This insures that the approach is comprehensive.

Cultural competency by health professionals and health systems in American Samoa is a key ingredient for the success of this plan.

The plan actively supports the recommendations and strategies found in other territorial plans that address cancer-related issues (e.g., the American Samoa Tobacco Prevention and Control Plan)

The cancer plan will be a road map of the efforts needed in American Samoa to reduce the cancer burden. Priorities will be set on greatest needs and most achievable, realistic strategies and actions. Due to the lack of data, strategies and actions will be based upon a five-year time span. This will allow for changes to be made as data becomes more available.

Some cancer efforts are currently underway in American Samoa. The territorial cancer plan will identify existing efforts and strive not to duplicate those efforts, but rather where appropriate, to build, enhance, and expand on them, for the benefit of all people in American Samoa.

Nutrition

Objective

1.3 By 2011, increase the amount of healthier foods (e.g. vegetables and fruits) offered in public schools by 20%

1.3a Develop policies within the DOE in accordance with guidelines from the ACS on Nutrition and Physical Activity for Cancer Prevention and the “5-A-Day” Program.

1.3b Educate public school food preparers and distributors on the importance of health diets.

1.3c Provide bottled water in school vending machines in place of sodas.

Objective

By 2011, increase the availability of culturally appropriate education and behavior change strategies that deal specifically with the increased consumption of fruits and vegetables.

1.4a Develop interventions that involve cultural norms for food preparation and the importance of addition of fruits and vegetables.

1.4b Develop a policy that nutritional values for menu items are posted in local restaurants.

1.4c Support the “5-A-Day” program objectives and activities at CCC implemented and/or sponsored events.

Physical Activity on a National level:

- The “President’s Challenge” educating and supporting all Americans on the importance of physical activity.
- School Health Policies and Program Study (SHPPS) survey assessing school health policies and programs (e.g. physical education) at the state, district, school, and classroom levels.
- In 2004, an estimated 17% of adolescents in the United States are overweight. (http://www.cdc.gov/nchs/products/pubs/pubd/hestats/obese03_04/overwght_child_03.htm)



Physical Activity in American Samoa:

- In 2005, adolescents from ages 11 - 18 were:
 - 29% of boys were considered overweight
 - 35% of girls were considered overweight
- Due to economic globalization, there are less physical activities that are part of daily routines for most American Samoans such as plantation work and fishing activities.
- Currently there is no mechanism to assess local school health policies and programs.

Although used synonymously, the CDC has separate definitions for the terms **Overweight** and **Obese**:

Overweight refers to increased body weight in relation to height, when compared to a medical standard of acceptable weight.



Obese is defined as an excessively high amount of body fat in relation to lean body mass. A determination of how an individual is overweight or obese is decided upon their Body Mass Index (BMI). This can be found by taking an individual's weight and dividing it by their height squared ($BMI = w/h^2$). Below is a table identifying the risk of associated disease according to BMI and waist size: With this information, physical activity objectives will focus on developing and implementing programs that increase physical activities in the daily



In order to reduce cross cutting issues between the American Samoa Department of Health (ASDOH) Tobacco Control and Prevention Program and Comprehensive Cancer Control (CCC) efforts, the American Samoa Community Cancer Coalition (ASCCC) focused on using collaboration of its organizational partnerships to increase the success of the current tobacco initiative.

Tobacco Use and Exposure

Objective

By 2011, decrease the number of teens in grades 9-12 who have used any form of tobacco product by 10%.

Strategies

- 1.1a Actively participate in efforts to decrease illegal tobacco sales to minors.
- 1.1b Raise awareness of Tobacco quitline and nicotine replacement therapy.
- 1.1c Lobby to raise cigarette tax and use funds to sustain current tobacco program, public health initiatives, access to health care, prevention, and/or family support for cancer control.

Objective

By 2011, increase the number of workplaces that offer a smoke free environment by 50%.

Strategies

- 1.2a Support efforts to promote smoke-free workplaces and facilities to local business owners.
- 1.2b Lobby to eliminate smoking at all government buildings.

Nutrition on a National level:

- Fast Food restaurants (e.g. McDonalds, Kentucky Fried Chicken, Pizza Hut) have included salads and nutritional facts on all menu items.
- School Health Policies and Program Study (SHPPS) survey assessing school health policies and programs (e.g. food service) at the

- state, district, school, and classroom levels.
- Statewide Nutrition Action Plan (SNAP) efforts funded by the United States Department of Agriculture.

Nutrition in American Samoa:

- Most meals are prepared with some type of starch (e.g. rice, breadfruit, and taro) that is high in calories.
- Fast Food restaurants do not provide nutritional menus or nutritional facts regarding menu items.
- Increased reliability for fast foods instead of more traditional meals⁷.
- Currently there is no Territorial or Statewide Nutrition Action Plan (SNAP) as set forth by the USDA.
- Currently there is no mechanism to assess local school health policies and programs.



ASBCCEDP annual Breast Cancer Awareness Walk-A-Thon 2006

American Samoa has become more westernized over the past 100 years of its relationship with the United States. As more foods are being imported into the territory and with the increase of two-worker families, residents are more reliant on fast foods instead of traditional diets that have less caloric intake. Nutritional objectives will focus on increasing support for local Food and Nutrition programs (e.g. 5-A-Day Program), education of the benefits of establishing and maintaining healthier diets, and the developing a mechanism to assess current and future activities that are provided in the territory.



With these guidelines in place, coalition members decided upon six priorities. The first four of these priorities dealt with the changing of cancer rates in American Samoa. The last two dealt with enhancing the infrastructure of American Samoa's cancer control. It was then decided that the coalition would divide into six workgroups that represented the cancer priorities and developed objectives, strategies, and actions for achieving these priorities. The cancer priorities that were agreed upon were:

Changing Cancer rates in American Samoa

Prevention

- Decrease Tobacco Smoking
- Educate the public regarding nutrition
- Increase the levels of physical activity

Early Detection

- Increase screening rates.
- Increase the screening capacity of health professionals.
- Maintain screening supplies.

Diagnosis/Treatment

- Decrease the amount of time a patient spends between diagnosis and treatment.
- Increase the healthcare capacity for treatment on island.
- Increase the laboratory capacity for diagnosing cancers on island.

Quality of Life

- Educate and improve quality of life services
- Assure that all cancer programs and services are comprehensive
- Reduce the financial burden

Enhancing Infrastructure of American Samoa's Cancer Control

Data

- Develop/improve the collection of set data
- Improve linkages
- Identify and implement new ways of turning data into action

Cost

- Reduce the financial burden for patients and/or their families.



Prevention Goals and Objectives

Prevent cancer from occurring with an emphasis on education and behavior changes.

The National Cancer Institute defines Prevention, as it pertains to medicine, as an:

“Action taken to decrease the chance of getting a disease or condition. For example, cancer prevention includes avoiding **risk factors** (such as smoking, obesity, lack of exercise, and radiation exposure) and increasing protective factors (such as getting regular physical activity, staying at a healthy weight, and having a healthy diet).”

Cancer prevention can be divided into three stages: **primary**, **secondary**, and **tertiary**.

- **Primary prevention:** refers to the complete prevention of disease, often through methods that inhibit exposure to **risk factors**. The four most important risk factors for cancer are **tobacco use, lack of physical activity, exposure to ultraviolet light, and poor nutrition**. Primary prevention is often used synonymously with prevention.
- **Secondary prevention:** activities detect disease early and limit disease effects after diagnosis. Outcomes for patients with breast cancer, for example, can be dramatically improved through early detection followed by appropriate treatment.
- **Tertiary prevention:** involves preventing further disability and restoring a higher level of functioning in someone with a disease. Like secondary prevention, tertiary prevention can involve treatment; however, it also includes rehabilitation and pain control.

Even though cancer pain can be relieved through proper therapies, the National Cancer Institute suggests that the undertreatment of pain is a serious and neglected public health problem.² To help alleviate this problem, programs should work with medical partners to ensure that cancer patients receive effective pain relief.

Risk Factors:

A risk factor is something that increases your chances of getting a disease. In terms of cancer, there are two commonly used risk factors: **Behavioral** and **Environmental**. Behavioral risk factors are those conditions or actions that may predispose an individual to a health problem to unhealthy behavior or lifestyle. For example, tobacco use is an acquired behavior and it increases your chances of developing many forms of cancer (i.e. lung, breast, colon, and prostate), therefore smoking cigarettes is a Behavioral Risk Factor for developing cancer. Environmental risk factors are influences in our surroundings such as radiation, chemicals and infections. In terms of the Pacific region, nuclear testing that was performed in the Republic of the Marshall Islands increased radiation levels in that area, causing an environmental risk factor for the surrounding populated islands to develop cancer.

Behavioral Risk Factors:

It has been estimated that from 50% to 70% of cancer deaths are attributable to preventable behavioral risk factors;¹ 30% of cancer deaths can be attributed to tobacco use and more than 30% to poor nutrition.² There is also strong evidence that physical activity is associated with a reduced risk of cancers of the colon, breast, prostate, lung, and endometrial (lining of the uterus) cancers³.

Environmental Risk Factors:

A major environmental risk factor for developing cancer is exposure to second hand smoke or environmental tobacco smoke (ETS). Currently, there are two forms of second hand smoke:

- Sidestream smoke: Smoke that comes from the end of a lighted cigarette, pipe, or cigar.
- Mainstream smoke: Smoke that is exhaled by a smoker.

When these two forms are present to nonsmokers, it is known as *involuntary smoking* or passive smoking⁵. Nonsmokers can inhale the same toxic chemicals and nicotine just as a smoker does. The greater the exposure to secondhand smoke, the greater risk of developing cancer becomes.

These behavioral and environmental risk factors can be modified, or changed, to reduce the incidence and/or mortality of cancer on island. However, in order to modify these factors, a better understanding of them on a national and territorial level needs to be explained.

Tobacco Use on a national level:

- Cigarette smoking causes 87 percent of lung cancer deaths and is responsible for most cancers of the larynx, oral cavity and pharynx, esophagus, and bladder⁴.
- Tobacco smoke contains thousands of chemical agents, including over 60 substances that are known to cause cancer⁴.
- Cigarette smoking is the single most preventable cause of death in the United States⁴.
- Smoking cessation has major and immediate health benefits, including decreasing the risk of lung and other cancers, heart attack, stroke, and chronic lung disease⁴.
- 46 states have legislation in place banning smoking in public places⁶.
- 49 states have legislation in place banning smoking in government buildings⁶.
- 33 states have legislation in place banning smoking in work places⁶.
- According to the CDC in 1997, approximately 25% of adults in the United States smoke.
- In 1992, the United States Environmental Protection Agency classified secondhand smoke as a Group A carcinogen (agents that are known to cause cancer for humans).

Tobacco Use in American Samoa:



In 2002, the Department of Health performed a Behavioral Risk Factor Surveillance System (BRFSS) survey throughout villages in American Samoa. The BRFSS survey monitors modifiable behavioral risk factors within a target group. At the time, 752 total surveys were conducted and the results were analyzed. The results included:

- 33% were currently smokers.
- The median age in which they began to smoke was 19.
- 30% had someone living in their home smoking inside.
- 74% had a child living in their home 17 years old or less.
- 80% of smokers tried to quit within the past 12 months of the survey.
- 65% of smokers would accept free treatment to help quit.
- 88% of all surveyed would try to help a child to quit smoking.

Non BRFSS related facts:

- Department of Health houses a Centers for Disease and Control (CDC) funded Tobacco Prevention and Control Program.
- Tobacco Quitline and Nicotine Replacement Therapy are available on island.
- No legislation banning smoking in public, government, or work places.
- Funds collected from cigarette tax are not used for tobacco or cancer prevention use.
- Lack of enforcing the illegal sale of tobacco products to minors.

After review of this information, objectives regarding limiting tobacco use and exposure in American Samoa will be focused on increased support of behavioral interventions for teenagers and increased support of policy changes that limit second hand smoke exposure in public and/or working places.