

**The Governor's Blue Ribbon Panel
on
Cancer Care in Hawaii**

**Final Report
May 2002**

EXECUTIVE SUMMARY

In November 1999 the Blue Ribbon Panel had been charged by the Governor of the State of Hawaii to examine and address issues related to reducing the burden of cancer in the people of Hawaii. The charges to the panel were:

- To review the availability, quality, and access to information, resources, and services currently available to Hawaii's cancer patients and their families.
- To review the barriers which prevent easy access to these information, resources, and services.
- To make specific recommendations for improvement.

The panel approached its task by:

- Looking at objective statistics and data which reflect the status of cancer care in Hawaii.
- Holding a series of community town hall meetings to obtain from patients, family members, caregivers, and the interested public their impressions of cancer care in Hawaii and their encounters with barriers to optimal care.
- Developing a proposal for optimal cancer care in Hawaii.
- Discussing the recommendations in the proposals with oncologists and hospital administrators in the community.

What we learned during the ensuing period of inquiry led us to make the following recommendations which are supported unanimously:

1. **That a comprehensive cancer control consortium (CCCC) be developed to address the primary prevention of cancer, cancer screening, and the early detection of cancer in Hawaii.**
2. **That an Outpatient Cancer Center be developed and located near the major hospitals and operated in partnership with community hospitals, practitioners, insurers, and the Cancer Research Center of Hawaii.**
3. **That neighbor island communities approaching population levels justifying a radiation facility receive state subsidies which permit construction and break-even for such a facility at the earliest possible time. That an alternative approach to this problem be a state-sponsored travel assistance to and housing program on Oahu, covering costs for the patient and one family member.**
4. **That greater emphasis be given to education for healthcare practitioners at all levels in the care of the dying person.**
5. **That secondary health plans supplement Medicare hospice benefits for symptomatic and palliative treatment procedures that are effective but not currently covered.**

PANEL MEMBERSHIP

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Cancer Incidence

Overall, Hawaii's world-standard, age-adjusted incidence rates for cancer exceed the world average. In Hawaii, for virtually every cancer site, one observes considerable ethnic variation in both incidence and mortality. Cancer incidence increases quite dramatically with age. Based on Hawaii's aging population, the number of Hawaii's citizens with cancer is expected to double over the next 30 years.

Behavioral Risk Factors Impacting on Cancer Incidence and Mortality

Risky habits are behavior patterns which result in an increase in cancer incidence and mortality. Tobacco use has been identified with causing a number of different cancers and is estimated to be responsible for about one-third of cancer deaths in the United States. In Hawaii, there is less cigarette smoking among Caucasians, Filipinos, and Japanese, compared to the 22.9% national average. There is more cigarette smoking among Hawaiians (26.2%).

Cancer Screening

Screening tests for some forms of cancer result in increased survival and decreased morbidity. A number of national cancer organizations have put forth guidelines for such testing. Compared to the national average, there is generally higher compliance with screening guidelines for Caucasians and Japanese, and lower compliance for Filipinos and Hawaiians.

Participation in Clinical Trials

Participation in clinical trials is a reflection of clinical cancer research in the state. Clinical trials are advocated to develop new standards of cancer treatment and to make available new drugs that are under development and which are available only on a research clinical trial basis. Participation in Hawaii is below the approximately 3% national average. In Hawaii, approximately 2.3% of patients with a new diagnosis of cancer participated in clinical trials in 1999.

Hospice Utilization

Individuals with cancer make up 85% of enrollees in the Medicare/Medicaid-certified hospices in Hawaii, compared to 60% nationwide. Average length of hospice enrollment in Hawaii was 40.6 days in 2000, lower than the 47 day national average. This suggests hospice referral later in the course of terminal illness. In one hospice organization's experience in Hawaii, 5% of patients die within 24 hours of enrollment. The data suggest that Hawaii's terminally ill cancer patients are not optimally utilizing the hospice benefits made available by Medicare, Medicaid, and the private insurance carriers.

Stage Distribution

The stage at which cancer is first detected is a surrogate measure of anticipated outcome from that cancer. Early stage at diagnosis is generally associated with increase in survival and curability. The greater numbers of early staged diagnoses versus late diagnoses usually reflect a more favorable screening activity and efficacy. Stage distribution for the more frequent cancer sites is generally favorable for Hawaii (i.e. higher proportion of early-stage and lower proportion of late-stage cases at time of diagnosis). An exception is in lung cancer, where the stage distribution in Hawaii is similar to the U.S. norm.

- Some testified that the professionals taking care of them seemed unaware of the emotional, cultural, and language barriers that prevent patients from hearing what is said to them regarding their disease.

Problems related to treatment and rehabilitation:

- Many in the rural sites expressed the desire to have the same services in their home communities that are available in a major cancer center.
- Many in the rural sites expressed difficulty with transportation to and from treatment sites, especially for radiation therapy.
- Very few have been told about clinical trials as an option.
- Too many are still uninsured or underinsured.
- Many patients expressed the desire to know more about complementary and alternative therapies.

Problems related to cancer survival issues:

- Many expressed there was a lack of patient support groups, especially in the language and culture of minority patients.
- Many patients felt they needed more information about cancer to help them cope with the future.
- Some expressed the need for better pain control.
- Some expressed the need for help in caring for a terminally ill person at home.

SUMMARY OF FINDINGS FROM THE TOWN HALL MEETINGS:

- There is a fragmentation of services from diagnosis to treatment.
- There is a need for more patient education and support.
- There is a need for an easier mechanism for patients to be entered into clinical trials.
- There are insufficient radiation oncology units in rural sites.
- Patients and families expressed a desire to have their treatment services closer to home.
- Patients and families from certain rural sites expressed a need for transportation to treatment centers.

PART III. PREVENTABLE CANCERS

The panel addressed the problems related to cancer care in Hawaii and offers the following proposals:

Preventable cancers

The prevention of preventable cancers must be very high among the priorities of a comprehensive cancer plan for the state of Hawaii. Cancers due to tobacco use account for about one-third of cancers nationwide and in Hawaii. Cancers that are caused by tobacco consumption are the most preventable of cancers, and they can be virtually eliminated by the elimination of the use of tobacco.

Recommendations for cancer treatment:

The Blue Ribbon Panel recommends the development of an Outpatient Cancer Center located near the major hospitals and developed in partnership with community hospitals, practitioners, insurers, and the Cancer Research Center of Hawaii. Such a center would enable the establishment of a more comprehensive clinical treatment program. This center would offer coordination of care, utilizing health educators, patient coordinators, and oncologic social workers. It should develop a cancer pain service, clinical trials support, comprehensive and expedited evaluation of the cancer patient, and multi-disciplinary treatment planning. To the extent possible, duplication of existing cancer care services should be avoided. However, we must be mindful that the inventory of future facilities must meet the needs of an increasing number of cancer patients due to population growth and an aging population. The Outpatient Cancer Center should enhance rapid and convenient access to care and should coordinate that care. An important goal is more efficient, coordinated initial care, linked with appropriate patient and family education, and when possible, the delivery of ongoing evidence-based cancer care in a setting close to the patient's home. Such a center should make more available participation in clinical trials.

The Outpatient Cancer Center, through its affiliation with the Cancer Research Center of Hawaii and the further development of a Statewide Clinical Trials System, would enable the establishment of a National Cancer Institute-designated Comprehensive Cancer Center in Hawaii. This would result in an increased availability of new treatments and clinical trials.

The development of an Outpatient Cancer Center will have an impact on the medical economics of the State as well as affect the quality of care of the cancer patients in Hawaii. We recommend that the State of Hawaii fund a study on the feasibility of such a plan and the impact of development of such an Outpatient Cancer Center would have on cancer care in Hawaii.

It is not the intent of the Outpatient Cancer Center to replace existing community resources for the treatment of cancer patients. It is expected that the Center would provide research, including drug clinical trials that are not currently available in the community. It is also expected that the Center would enhance the treatment planning and consultative services that currently exist in the community so that patients who now feel the need to go out of state for consultative services would feel less of a need to do so.

Recommendations for enhanced Radiation Therapy Access:

It has been noted that there are communities in Hawaii which do not have ready access to radiation therapy facilities, making the populations of these communities forego the benefits of radiation therapy or else experience undue hardships to obtain these treatments. It is recommended that communities approaching population levels justifying a radiation therapy facility receive subsidies, thus permitting construction and break-even for such a facility at the earliest possible time.

An alternative approach to this problem would be a state-sponsored travel assistance and housing program, covering costs for the patient and one family member. With such a program, temporary residence near a radiation facility will make this treatment more accessible for all patients.

Appendix I

Report on the Status of Cancer Care in Hawaii Governor's Blue Ribbon Panel on Cancer Care in Hawaii Committee on the Status of Cancer Care in Hawaii

Chair: Scott Hundahl, M.D., F.A.C.S.

Committee Members: Brian Issell, M.D., F.A.C.P.; Patricia Kalua, R.N., M.A.O.M.; Laurence Kolonel, M.D., Ph.D. (guest member); Virginia Pressler, M.D., M.B.A.; Carl-Wilhelm Vogel, M.D., Ph.D.; and Robert Wilkinson, M.D.

EXECUTIVE SUMMARY:

Hawaii Demographics

- Age: As elsewhere in the U.S., Hawaii's population is aging. Age distribution in Hawaii varies considerably by ethnic group.
- Ethnicity: According to 2000 Census data (released May 18, 2001), a diverse mix of ethnic groups make up Hawaii's 1,211,537 population: 1.8% African American, 24.3% Caucasian, 4.7% Chinese, 14.1% Filipino, 9.4% Hawaiian/Other Pacific Islander, 16.7% Japanese, 1.9% Korean, and 27.1% Mixed/Other.

Cancer Incidence

Overall, Hawaii's world-standard, age-adjusted incidence rates for cancer exceed the world average. In Hawaii, for virtually every cancer site, one observes considerable ethnic variation in both incidence and mortality. Cancer incidence increases quite dramatically with age. Based on Hawaii's aging population, the number of Hawaii citizens with cancer is expected to double over the next 30 years.

Behavioral Risk Factors Impacting on Cancer Incidence and Early Detection

- Risky Habits: Less cigarette smoking for Caucasians, Filipinos, and Japanese, compared to the 22.9% national average. Relatively more cigarette smoking for Hawaiians (26.2%).
- Screening: Compared to the national average, generally higher compliance with screening guidelines for Caucasians and Japanese, and lower compliance for Filipinos and Hawaiians.

Participation in Clinical Trials

Data is sub-optimal, but participation seems slightly below the approximately 3% national average. In Hawaii, approximately 2.3% of patients with a new diagnosis of cancer participated in 1999.

Hospice Utilization

Individuals with cancer make up 85% of enrollees (vs. 60% nationwide) in the Medicare/Medicaid-certified hospices in Hawaii. Average length of hospice enrollment in Hawaii was 40.6 days in 2000, lower than the 47 day national average. This suggests hospice

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Data Committee Report (Handouts & Tables)

Demographics & Incidence – Laurence Kolonel, M.D.

Tables – Cancer Incidence In Hawaii & Trends – Hawaii Tumor Registry

Behavioral Risk Factor Surveillance Survey Data For Hawaii - Virginia Pressler, M.D.

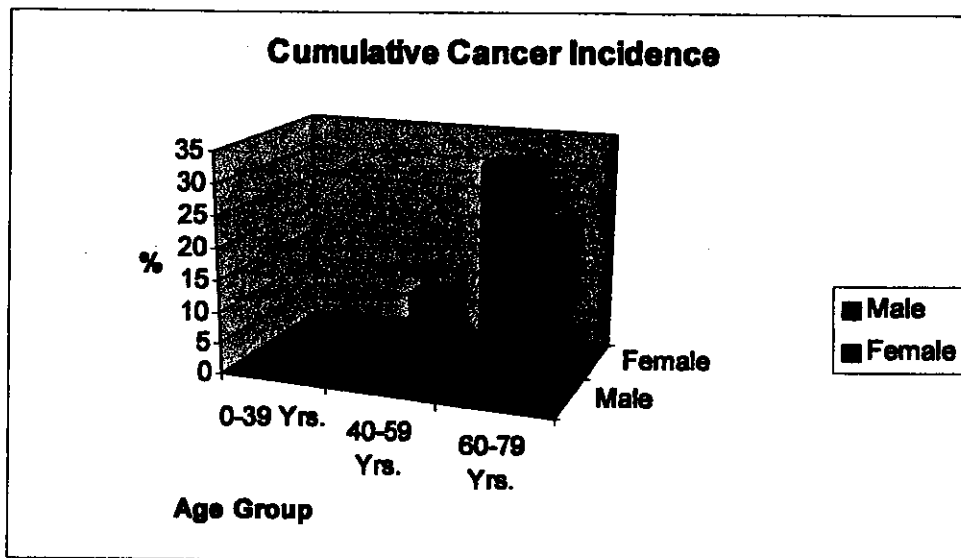
Hospice in Hawaii – Patricia Kalua, R.N.

Clinical Trials in Hawaii – Brian Issell, M.D.

Cancer Care & Outcomes, Hawaii vs. U.S. – Scott Hundahl, M.D.

Cancer Incidence

Cancer incidence increases quite dramatically with age, a fact sometimes obscured by the age adjustment intrinsic to the calculation of standardized incidence rates. For example, based on 1993-1995 data, the American Cancer Society estimates that cumulative percentage of Americans developing cancer is as follows:¹



A greater proportion of Hawaii's citizens are migrating into the 60-79 year, higher-cancer-risk category. The absolute number of cancer cases in Hawaii will increase as a result. While trends in age-adjusted cancer incidence are indeed observed over time (see below), the effect of an aging population generally outweighs all other factors. Conservatively, based on the aging population, the absolute number of Hawaii citizens with cancer is expected to double over the next 30 years.

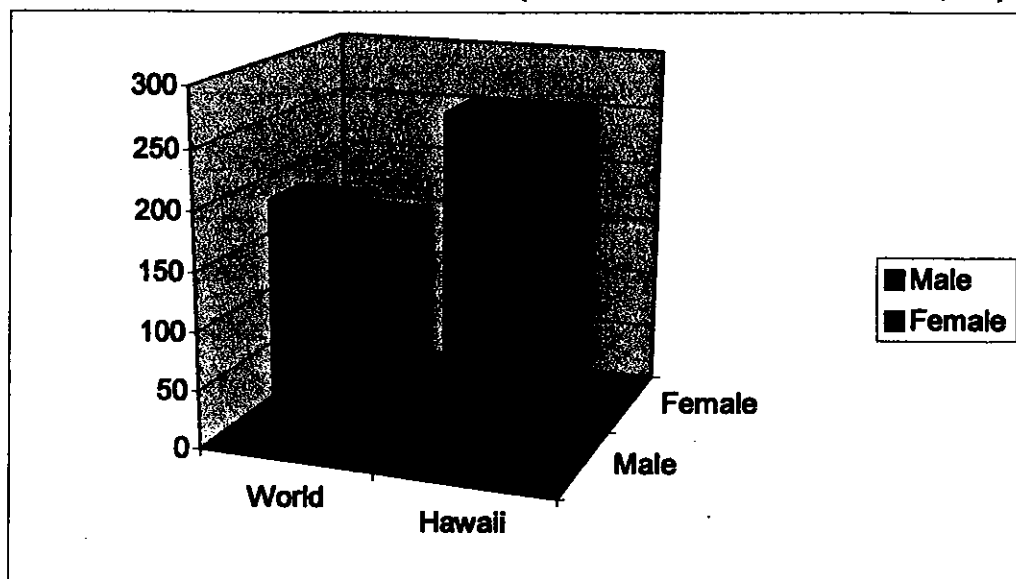
As documented in the incidence tables found in the *Appendix*, cancer incidence also varies according to ethnicity. As of this writing, the most recent incidence data for Hawaii is for the 1986-1990 period. As soon as 2000 census data can be mined for accurate denominators, updated, accurate incidence data for the 1990's will be available.

Based on Hawaii Tumor Registry data for the 1986-1990 period, the incidence of invasive cancer by ethnicity, age-adjusted to the World Standard Population is as follows:

¹ Landis SH, Murray T, Bolden S, Wingo PA. Cancer statistics, 1999. *CA-J for Clin* 1999; 49: 8-31.

How does cancer incidence in Hawaii compare to that of the rest of the world? The answer to this question is somewhat confounded by the vast differences in the quality of case-finding, cancer registration, and data systems around the world. Developing nations generally have poorer systems, and this results in under-estimation of true cancer incidence. Keeping this drawback in mind, however, worldwide incidence of invasive cancer has been estimated by Parkin et al. working under the auspices of the The International Agency for Research in Cancer (IARC) in Lyon, France.² Comparison with Hawaii incidence rates is depicted below:

Cancer Incidence, World Vs. Hawaii (World Standard Rate Per 100,000)



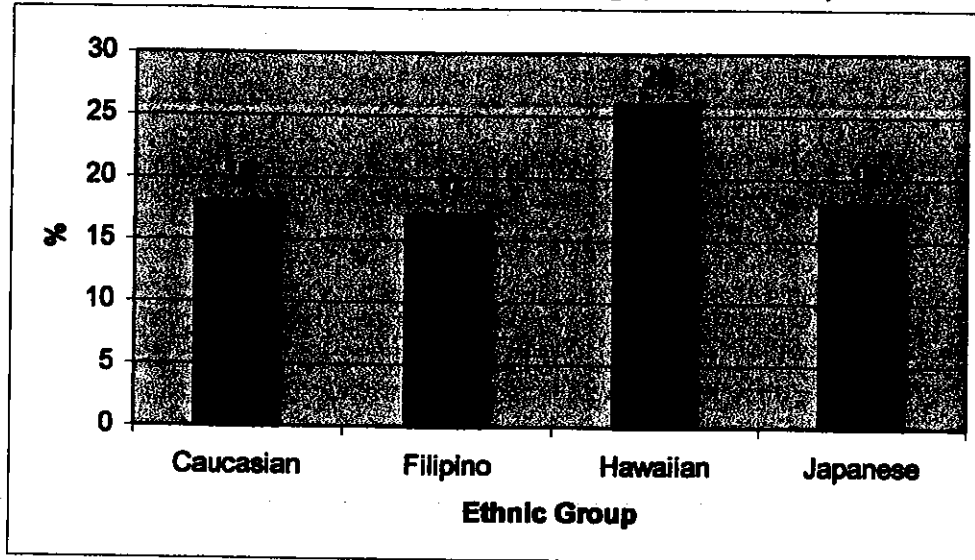
Cancer Incidence, World vs. Hawaii (World Standard Rate Per 100,000)

	World	Hawaii
Male	203	284
Female	154	256

More recent data concerning proportional cancer burden (i.e. top cancer sites), treatment, and stage-stratified survival is available through the National Cancer Data Base (N.C.D.B.). The N.C.D.B. accessions 100% of reportable cancer cases in Hawaii and approximately 70% of cancer cases nationwide (i.e. 100% of cases at participating hospitals & registries, but not all hospitals participate). N.C.D.B. data for patients treated 1994-1995 illustrate that proportional cancer burden in Hawaii closely mirrors that of the U.S. as a whole:

² Parkin DM, Pisani P, Ferlay J. Global cancer statistics. CA-Cin J Clin 1999; 49: 33-64.

Adults Currently Smoking, By Ethnic Group (Hawaii, 1998)



National Average: 22.9%

Hawaii Average: 19.4%

As depicted in the *Appendix*, B.R.F.S.S. data also address compliance with national guidelines for cancer screening. In general, compliance with cervical cancer (i.e. exam and PAP test), colorectal cancer [i.e. Fecal Occult Blood Test (FOBT) and sigmoidoscopy], and breast cancer (i.e. exam and mammography) screening and early detection guidelines was higher than the national average for Caucasians and Japanese living in Hawaii, and lower for Filipinos and Hawaiians.

Participation in Clinical Trials

State data concerning participation in cancer clinical trials is derived from records of the Cancer Research Center of Hawaii (C.R.C.H.). The Committee recognizes that such data is incomplete; individual clinicians and institutions occasionally do participate in cancer clinical trials outside of C.R.C.H. mechanisms. The vast majority of those participating in cancer clinical trials in Hawaii do so through the C.R.C.H., however.

As depicted in the *Appendix*, statewide participation rates over the past decade have averaged between 2% and 3.3% of new cancer patients. Participation rates are falling. In 1998, 2.5% of patients with a new diagnosis of cancer participated. In 1999, 2.3% participated. The national average is approximately 3%.

Participation rates vary considerably by hospital and by patient population. Paralleling excellent participation rates nationwide for pediatric patients, 56% of pediatric cancer patients in Hawaii participated in clinical trials in the 1998-1999 period. Adult participation rates are much lower: 2.0% for adults treated at community hospitals in Honolulu and 3.6% for adults treated at Tripler

data for breast cancer, the Chair's review of pattern-of-care data for colon cancer and rectal cancer also reveal better compliance in Hawaii compared to national norms.

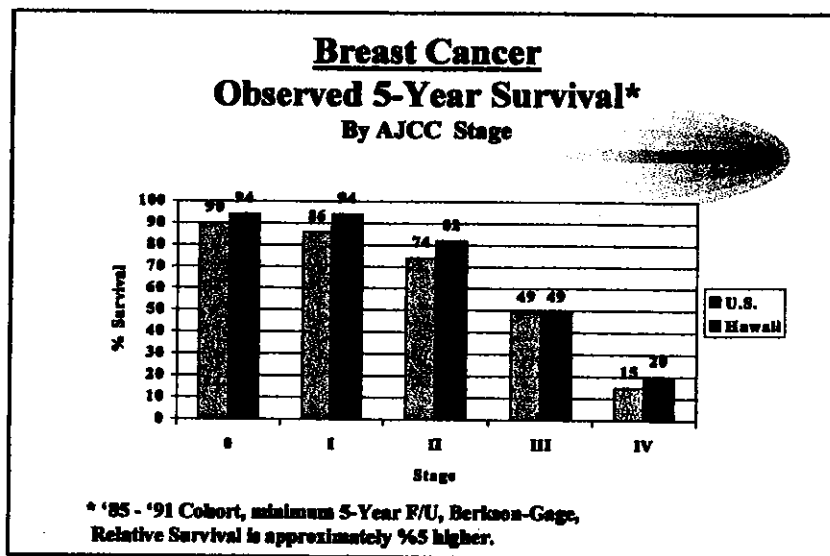
It is certainly recognized that cancer treatment decisions are complex and must be tailored to the specific features of each case. Co-morbid, non-cancerous medical conditions certainly warrant occasional deviation from what is considered standard treatment. Patient attitudes, knowledge, and personal choice also play an important role. There is very little national or statewide data addressing the reasons why standard treatment guidelines are not followed in particular cases. This is an area of future investigation.

Stage-for-Stage 5-Year Survival Rates

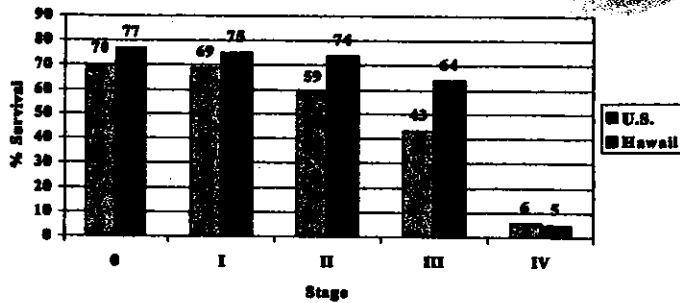
Cancer stage generally reflects the extent to which a patient's cancer has spread. American Joint Committee on Cancer (A.J.C.C.) staging is generally used by clinicians to guide treatment decisions and estimate prognosis. A.J.C.C. Stage 0 reflects non-invasive disease with an excellent prognosis. Stage I disease reflects early invasive disease. Stage IV disease reflects advanced disease, usually with spread to distant organs, and often with a dire prognosis.

N.C.D.B. data for Hawaii cases treated in the 1985-1991 period and followed for 5 years was reviewed in detail by the Committee. Survival rates were compared, stage for stage, for all of the top cancer sites previously described. Hawaii stage-stratified survival rates were generally superior to mainland norms.

Examples of the favorable stage-for-stage survival comparison between Hawaii and the U.S. are depicted below:



Colon Cancer
Observed 5-Year Survival*
 By AJCC Stage



* '85 - '91 Cohort, minimum 5-Year F/U, Berkson-Gage, Relative Survival is approximately 5% higher.

Overall 5-Year Survival Rates

N.C.D.B. data for patients treated 1985-1991 and followed for 5 years, reveals that, as a result of generally favorable stage distribution for Hawaii cases, better-than-average compliance with standard treatment recommendations, and favorable stage-stratified survival rates, Hawaii patients enjoy dramatically better cancer survival for all of the top cancer sites, with the possible exception of lung cancer.

Overall 5-Yr. Observed Survival*

	<u>U.S.</u>	<u>Hawaii</u>
Breast	74%	84%
Lung	11%	13%
Prostate	60%	70%
Colon & Rectal	48%	60%

*NCDB, '85-'91

Overall Observations

While the outcomes associated with cancer treatment in Hawaii are measurably superior to

Appendix II

Report of Findings from Public Hearings and Survivor Issues Governor's Blue Ribbon Panel on Cancer Care in Hawaii Cancer Survivors Committee

Committee Members: Jonathan Brookfield; Rev. Frank Chong, M.S.W., M.Div.; Ann Kobayashi; Chris Pablo, Esq.; and Jackie Young, Ph.D.

The testimonies of cancer survivors obtained during the statewide public hearings were wide-ranging, as were their cancers. Some were recently diagnosed, but there were also long-term survivors. The problems and needs expressed from the testimonies were grouped in four stages: **early detection, diagnostic period, treatment and rehabilitation period, and aftercare.**

1. EARLY DETECTION

- **Awareness** - Survivors testified that the availability of screening programs in their communities was minimal to nonexistent. Also, many people were unclear as to who would pay, or who qualifies for the more invasive screening tests such as colonoscopy, mammograms and pap smears.

Expressed Need: It is urgent that public policies support a dramatic increase in awareness and education programs.

- **Reaching the hardly reached** - There are geographic pockets in Hawaii where populations suffer from inordinately high cancer mortality rates often due to late detection of their cancer. For example, public awareness campaigns do not seem to be effective in reaching populations such as native Hawaiians, Filipinos, and recent immigrants of the need for regular screening for early detection.

Expressed Need: Special public awareness programs need to be developed to connect with those who are at the highest risk for death from cancer due to diagnosis at advanced stages.

2. DIAGNOSTIC PERIOD

- **Sensitivity of professionals** - Many professionals seem unaware of the emotional, cultural and language barriers that prevent patients from "hearing" what is being said.

Expressed need: Translation considerations at time of diagnosis as well as an empathetic manner by doctors would lessen the initial impact from the diagnosis and assist patients in questioning, understanding and accepting active involvement in the life-changing series of events to follow.

Expressed Need: Clinical trials are an option that needs to be offered to cancer patients.

- **Complementary and Alternative therapy** - People want to be seen as a whole person and not viewed through a diseased body part. The use of complementary therapies is a rapidly growing trend.

Expressed Need: Patients would like to be able to discuss their healing practices with doctors who are genuinely open to complementary therapies as part of their cancer care.

4. AFTERCARE (OR LONG TERM CARE)

- **Living with Cancer** - Quality of life issues are ever present once cancer is diagnosed. Once treatment is completed, cancer survivors are expected to live a normal life. But what is "normal" when the specter of recurrence and metastasis is ever present?

Expressed Need: Cancer survivors testified that regular updates on latest research findings give them hope. As does complementary therapies. As does love, humor, and an ever present spiritual and support network.

- **Dying from cancer** - For some cancer patients these four stages of cancer survivorship are compressed over a short period of time.

Expressed Need: Whether one goes quickly or slowly, the presence of a support network should not be an option. Ideally, living with pain should never be an option.

In the United States, only 23.9% of the diet of adults include five or more servings of fruits and vegetables per day. In Hawaii only 27.5% of adults follow this guideline.(3)

Obesity is associated with an increased risk of cancer of the breast, uterus, ovary, and gallbladder in women. Women who are more than 35% above their ideal body weight are about 1.5 times more likely to develop these cancers than their non-overweight counterparts.

Among men, obesity is associated with an increased risk of cancer of the colon and prostate. Men who are more than 35% above their ideal body weight are 1.4 times more likely to develop these cancers than lean men.

The Centers for Disease Control and Prevention reported from their Behavioral Risk Factor Surveys that 36.2% of adults in the U.S. are overweight and 16.5% are obese. The same survey indicated that 34.3% of adults in Hawaii are overweight and 15.7% are obese.(4)

Cancer Screening

Early detection of cancer has been shown to improve survival for a number of cancers, including breast cancer in women, cancer of the colon and rectum, cancer of the cervix, cancer of the testes, oropharyngeal cancers, and skin cancer. The early detection of cancer of the prostate improves the stage of cancer at the time of diagnosis, and the survival of prostate cancer patients has improved since the development of screening techniques. In all of these cancers, patients diagnosed in an early, or localized, stage can be cured. If all these cancers were diagnosed at a localized stage, the relative survival rate would increase to 95% respectively.(5)

Effective cancer screening procedures have been devised for many cancers. Mammography has been shown to detect breast cancer at earlier stages, and its use has been demonstrated to improve survival and the quality of life of patients who develop this cancer.

Since the introduction of the Pap test in the 1950s, the incidence and mortality rates of cancer of the cervix have dropped markedly.(6) Cervical cancer is one of the most treatable cancers when detected early, with a 5-year survival rate of 92%. The percentage of women in the U.S. who have had a Pap test within the past three years were 88.3% in the 18-44 year age group, 81% in women 45 years and older, and 72.3% in women over the age of 65. The corresponding percentages for women in Hawaii were 87.6%, 86%, and 80.9%.(4)

Cancer of the colon and rectum is the third most common cancer among U.S. men and women and the second leading cause of cancer deaths when men and women are combined. Survival from this cancer is excellent when detected in an early, or localized, stage. At this stage, the 5-year survival rate is 90%. However, when the cancer has spread to lymph nodes and the surrounding tissue, the 5-year survival falls to 65%.(7) Screening examinations for colon and rectal cancers include testing for fecal occult

3. American Cancer Society. Cancer Prevention and Early Detection, Facts and Figures 2001. Atlanta, GA; 2001.
4. The Behavioral Risk Factor Surveillance System CD-ROM 1999, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention 2000.
5. American Cancer Society. Cancer Facts & Figures 2001. Atlanta, GA; 2001.
6. Schiffman MD, Brinton LA, Devesa SS, Fraumeni J, Joseph F. Cervical Cancer. In: Schottenfeld D, Fraumeni J, Joseph F., eds. Cancer Epidemiology and Prevention. New York: Oxford University Press; 1996.
7. Ries LAG, Eisner MP, Kosary CL, et al. SEER Cancer Statistics Review, 1973-1997. Bethesda, MD: National Cancer Institute; 2000.
8. US Department of Health and Human Services. Healthy People 2010 (Conference Edition, in Two Volumes). Washington DC: US Department of Health and Human Services; 2000.

Cancer patients must be provided access to state-of-the-art treatments as new drugs and treatments are developed. The Blue Ribbon Panel recognizes that our clinical trial infrastructure must be enhanced in order to increase access to new cancer treatments and improvements in care. Biotechnology is beginning to deliver relatively non-toxic, effective, new treatments for cancer. By their very nature, such treatments are first available through clinical trials. In the setting of potentially curative treatments where none previously existed, clinical trial access can translate into lives saved.

The current fiscal climate and declining reimbursements challenge our health care system at many levels. This report alone will certainly not remedy the situation, nor will vision alone generate the improvements in cancer care we propose. Improvements require attitude shifts, system revisions, and funds. Nonetheless, recognizing we have existing areas of excellence to build on, we see a clear opportunity to enhance our cancer care infrastructure and thus lessen the burden of cancer on patients and their families. We believe this can be accomplished in a responsible, cost-effective manner.

The following recommendations are based on the Report of the Subcommittee on the Status of Cancer Care in Hawaii; review of the findings of the Cancer Survivors Subcommittee; review of the National Cancer Policy Board's report, *Ensuring Quality Cancer Care*; public hearings hosted at virtually every major hospital in Hawaii; and local/regional/national information shared by members of the Blue Ribbon Panel. At the public hearings, a diverse group of patients and their family members, as well as medical professionals, shared their experience and perceptions of cancer care in our state.

Optimal Care

The Blue Ribbon Panel embraces a concept of evidence-based cancer care with the following characteristics:

- Accessible (i.e. access to all treatments of proven efficacy and trials of new treatments)
- Patient-centered
- Timely
- Competent
- Multidisciplinary
- Compassionate
- Coordinated
- Reliable
- Cost-effective
- High quality (with measurable outcomes)

Identified Areas for Improvement

Independent private practitioners and open community medical centers currently provide the majority of cancer care in Hawaii. Kaiser Permanente and Tripler Army Medical Center/Veterans Administration are integrated hospital-based organizations delivering cancer care to a minority of

to centralized settings where trained health professionals can assist practitioners in meeting this challenge, the burden in Hawaii falls solely on the practitioner's shoulders. Most practitioners wish they had some assistance in this area. All patients should be well informed about the nature of their condition, its natural history, what treatment options are available, the morbidity and anticipated outcomes associated with such treatments, and the availability (or lack thereof) of specific high-quality clinical trials. Given the physical demands of many treatments, combined with their sometimes sub-optimal results, every patient must be encouraged to participate in making decisions about their treatment to the degree they wish.

The scheduling of imaging tests and consultant visits can also represent a challenge. In the current, decentralized system, practitioners and their staff constantly struggle with this. Patient and family convenience is frequently sacrificed in favor of timely completion. Cancer patients usually do not receive prioritized treatment in imaging facilities, which normally run on a sequential, "first-scheduled-first served," appointment basis. In the area of scheduling, coordinating visits, etc., a trained "coordinator" (also known as "health care navigator," or "care concierge") might do much to ease the burden on patients and their families.

The panel recognizes the special challenges associated with end-of-life situations. Unrealistic expectations can certainly fuel a march to futile medical interventions, which ultimately detract from the quality of life remaining. Lingering, painful demise in an intensive care setting, surrounded by machines and strangers instead of loved ones, contrasts sharply with the hospice experience. Sensitive, compassionate educational efforts concerning care options is particularly important in palliative settings. Better integration and coordination of palliative care and hospice care services can make a tremendous difference to patients and their families.

2. Access to state-of-the-art, high-quality treatment (including clinical trials)

Almost all standard, scientifically validated treatments for cancer are currently available here in Hawaii. As noted, new, less-toxic, more effective treatments are emerging as a result of advances in biotechnology and tumor biology. Such treatments may be in the form of a simple pill (e.g. STI-571 for chronic myelogenous leukemia, CML) or other, more complicated, technologies/modalities. By their nature, such treatments are first available through clinical trials.

Today, overall, 40-50% of cancer patients will not be cured by today's standard treatments. Particularly at a time when biotechnology is producing curative treatments for previously fatal conditions, broad access to clinical trials should be a priority. The National Institutes of Health, in a report to the Senate Appropriations Committee, recently stressed:

"For patients with life threatening disease for which standard therapy is inadequate or lacking altogether, participation in well-designed, closely monitored clinical trials represents best medical care for the patient. The National Cancer Institute believes that clinical trials are standard therapy for cancer patients to whom a curative therapy cannot be offered."

Kona/North Hawaii, Molokai and Lanai). In the case of Molokai and Lanai residents, daily travel by boat to the facility on Maui is possible, but inconvenient, as is travel by road to Hilo for Kona/North Hawaii residents. Long daily travel represents a particular burden for patients not feeling well. Because patient access to radiation therapy is important, we believe either of two options can work:

- Communities approaching population levels justifying a radiation therapy facility should receive subsidies, thus permitting construction and break-even for such a facility at the earliest possible time.
- A state-sponsored travel assistance and housing program, covering costs for the patient and one family member. With such a program in place, temporary residence near a radiation facility will be possible for all patients.

Staff:

There is a need for **trained care coordinators and health educators**, who, working with the care team (i.e. experts in medical oncology, radiation oncology, and surgical oncology, as well as practitioners in the related areas of genetics, symptom control, palliative care, and health education), help patients navigate through the system. Such individuals would be poised to assist at each of the following steps in care delivery:

- Consultation
- Extent-of-disease imaging
- Multi-disciplinary treatment planning and recommendations
- Education for patients and their family members
- Informed decision making (including option of clinical trial participation where appropriate)
- Treatment delivery.

Hawaii has excellent community practitioners who, although often separated, are reasonably well networked with colleagues throughout the state. Through the infrastructure provided by the aforementioned outpatient center, which functions as a clinical coordinating center, enhanced, integrated care would be possible.

Community clinical oncologists and CRCH clinical researchers would comprise a team of **clinical investigators** who would contribute to a robust, statewide, **clinical trials system**. The Cancer Research Center of Hawaii is poised to support such individuals, but requires additional funding to accomplish this. In the context of Hawaii's current system of care, our current clinical trials infrastructure is fragile and seriously under-funded. For a sustained effort, reliable funding and clinical research appointments will be required. Further, third party payers should be required to cover the costs of clinical care for individuals participating in clinical trials. By Presidential Order, in September 2000, Medicare now covers the cost of standard care for patients participating in government-sponsored clinical trials.

An active clinical trials support staff and infrastructure should be part of the aforementioned outpatient center. Clinical investigators, working with other experts available through existing hospitals and the Cancer Research Center of Hawaii (e.g. pharmacologists, pathologists, data

residence near a radiation facility will be possible for all patients.

4. **Hospice and palliative care enhancements:**

- **Expand eligibility criteria (at the federal, Medicare level) from 6 months prognosis to one year.**
- **Encourage continued Medicare and insurer coverage for certain therapies after hospice supportive care has been initiated. For example, a patient may benefit from continued chemotherapy in conjunction with palliative hospice services but this is usually precluded under the current reimbursement structure. This often inhibits hospice election by patients and their families. Further, this tends to discourage some types of appropriate palliative care. A Medicare demonstration project seems reasonable.**
- **Include palliative care and hospice studies in the aforementioned clinical trial structure and include existing Hawaii hospice organizations as part of the network.**

program, the Last Acts Coalition, and the End of Life Nursing Education Consortium, to name only three.

Second, the Medicare hospice benefit (and others) do not provide hospice organizations with the financial resources to provide such treatments as palliative chemotherapy and radiation. Hospice reimbursement is capitated. The current reimbursement to a Medicare certified hospice program for a patient at home with all of the services listed above is approximately \$131.00 per day. Hospice programs cannot bill separately for any service that is identified as palliative. In other words, a hospice program cannot bill a secondary health plan for a treatment deemed palliative by a physician, such as chemotherapy or radiation. It is also difficult for physicians to "precisely guess" a patient's prognosis. This means that patients and physicians feel they must "give up treatment" in order to access hospice and all that it offers. This could be avoided if the patient's secondary health plan could supplement the hospice benefit for certain treatments or provide concurrent coverage for hospice as a patient transitions to hospice from an acute or rehabilitative setting or plan of care.

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