

What is a cancer registry?

- A cancer registry is a special database that contains information about cancer patients in a particular population (jurisdiction) or in a particular hospital. A registry contains many special reports call abstracts. An abstract is a summary of a patient's medical record, but the information is collected in a standardized way. There are generally 3 types of information collected in an abstract:
 - Patient-specific information: This is information that generally does not change over time. This allows the registry to compare reports and make sure that there are no duplicate patients in the database. Information gathered includes identifying information, what ethnicity are they, where were they born, do or did they work in an job that could have contributed to the patient developing cancer, do they have risk factors for cancer, what other types of diseases or conditions do they have that could impact their cancer care and treatment?
 - Cancer-specific information: This information describes the patient and cancer at the time the patient was first diagnosed. What type of cancer and how advanced, where were they diagnosed, what types of treatments did the patient receive?
 - Hospital or facility information: This includes the patient record number, insurance information, date of admission and discharge and other items.

Why is a cancer registry needed if that information is already noted in the medical record?

- Many times, cancer patients get diagnosed or treated in different places, especially in jurisdictions that send patients off-island for advanced medical or surgical care. Additionally, some patients unfortunately develop more than one type of cancer. The registry is responsible for combining the different abstracts or reports into one record for that patient. The combined or consolidated abstract relates the events leading to the diagnosis of cancer through the initial treatment of the identified cancer. The Pacific Regional Cancer registry will also be collecting additional follow-up information (what happened to the patient 1 year, 5 years, 10 years after the initial diagnosis).
- A cancer registry collects, reviews and analyzes information in a standardized way. This allows comparison of high quality information, which can then be used to help evaluate medical and public health services and programs. Over time, the information can be used to improve patient care.
- The type of information maintained by a cancer registry is called "surveillance" data. This means the health officials in each location can monitor cancer and can determine trends and improvements (hopefully) in the ability to detect cancer early or to treat it more effectively. The Pacific Regional Cancer Registry will also track risk factors associated with the known cancers; this should help to better target education, outreach and screening programs in each jurisdiction and throughout the USAPI region.

Why do we need a Cancer Registry Act (Law)?

- In order for the Department or Ministry of Health to do the best job it can to protect and keep people healthy, certain diseases and conditions need to be reported. The Department or Ministry of Health is responsible for monitoring and tracking disease across the entire population, and also responsible for planning and delivering appropriate services and programs to keep the people as healthy as possible.
- Unless there is a law that requires reporting to the Department or Ministry of Health, some physicians or private facilities may not share the correct information. In order for the DOH/MOH to monitor disease in the entire population, everyone must report. Otherwise, the information will be incomplete.
- A Cancer Registry Act (Law) also protects individuals and facilities who report cancer cases from liability.

How is patient confidentiality maintained?

- Existing policies and procedures that protect patient health information will be strengthened.
- If needed, health workers will undergo training on how to keep the patient information confidential
- Relevant health personnel will sign a Confidentiality Agreement
- Each Department/Ministry of Health will go through a process to decide on penalties for those who intentionally disclose patient information

How will the information remain secure?

- All medical records rooms/departments should be locked and not accessible to the general public.
- Any fax machine used to transit patient information should be in a private office (somewhere not accessible to the general public).
- The computer(s) with the patient information should have appropriate security and back-up measures in place.
- Information from the patient chart or other reports will be entered into a special software program (Abstract Plus). The software requires a user name and password to operate. The software is also highly specialized and contains many numerical codes, so an untrained person would not be able to understand the information on the screen.
- Information to be sent to the Pacific Regional Central Cancer Registry is encrypted. It will either be put onto CD-ROM and mailed via courier or may be transmitted over the Internet if appropriate security and speed allows for transmission of that information. The encrypted information can only be accessed by someone with the same software program, a user name and password and appropriate training.

Why does the information in our jurisdiction cancer registry need to be sent to the Pacific Regional Central Cancer Registry?

- The overall numbers of cancer cases in the Pacific are relatively small in comparison to most States in the U.S. When overall numbers are small, it is sometimes difficult to draw meaningful conclusions or to present data that

will convince policy makers and funders of the magnitude of the cancer problem in the Pacific. Since the Pacific Cancer Initiative started in 2002, U.S. Federal agencies and others have “paid more attention” to the cancer issues and other challenges facing the Pacific because the Region was able to come together and gather information in a more standardized way (the 2002 Cancer Needs Assessments). Simply put, there is more strength in numbers and the information is more convincing if the data is collected in a standardized way, in adherence with high quality standards.

- The Pacific Central Registry will also be able to combine (consolidate) information from multiple sources, so minimize the chance that a cancer patient is “lost to follow-up”. For example, a patient from American Samoa might have suspicious symptoms for cancer while in American Samoa. However, they come to Hawaii and receive the diagnosis. They may receive different treatments at 3 different hospitals or facilities on Oahu. The Hawaii Tumor Registry would collect that information. The patient may then move to California and develop a new cancer 7 years later. This new cancer information will be collected in the California Cancer Registry. At present, some patients do not return to their original doctor/hospital for the remainder of care and so the jurisdiction has no further information about that patient. Agreements will be put in place so that the information can be shared between the Regional central cancer registry, the Hawaii Tumor Registry, the Manila Cancer Registry and others (where there might be a high concentration of USAPI residents getting care). Whatever information comes into the Pacific Central registry will be compiled and eventually relayed back to the jurisdiction.
- Some of the jurisdictions have such small numbers of cases and limited staff and personnel, that it may not be feasible to develop a fully functioning cancer registry. The jurisdiction cancer data personnel will learn to abstract as much of the cancer cases as possible. They will then transmit that information to the central registry, where the central registry staff will work on completing and coding the abstract.

What is the general flow of information for patients with cancer?

- Physicians, nurses, hospital lab, public health and off-island referral offices will report basic information to the jurisdiction registry. The registry staff will then seek additional information that is required.
- Once the information is gathered and/or reported to the DOH/MOH, the cancer program staff will need to enter that information into the Registry software. After the information is entered, the abstracts need to be checked for accuracy and completeness. Once the abstracts are as complete as possible, the information needs to be sent to the Pacific Regional Central Cancer Registry. The Central Registry staff then looks for duplicate records, combines the abstracts and does additional tests to make sure the information is accurate and complete.
- In the FSM, each State will report their registry information to the FSM National cancer registry. FSM National will run additional tests to assure accuracy and completion. The FSM National registry will work with the States to follow-up on any information that is incomplete or inaccurate. The FSM

Registry will share that information with the Pacific Regional Central Cancer Registry.

What role does the University of Hawaii (UH) have in developing our jurisdiction cancer registry?

- The University of Hawaii, John A. Burns School of Medicine, Department of Family Medicine has been working with the USAPI since 2002 to help each jurisdiction and the Region develop strategic plans to prevent and combat cancer.
- One outcome of this strategic planning process was a decision to develop a Regional Cancer Registry. The UH was awarded a cooperative agreement from the US Centers for Disease Control (CDC) to develop a Regional Cancer Registry on behalf of the six USAPI jurisdictions.
- The University of Guam (UoG), Guam Department of Public Health and Social Services (GDPHSS), Guam Cancer Coalition (GCC), and both the John A. Burns School of Medicine, Department of Family Medicine and Community Health, (JABSOM-DFMCH) and the Cancer Research Center of Hawai'i, Hawai'i Tumor Registry (CRCH/HTR) of the University of Hawai'i have partnered to develop and operate two Guam based cancer registries. They are the Guam Cancer Registry (GCR) and a Pacific Regional Central Cancer Registry (PRCCR), a Regional Cancer Registry for the US Associated Pacific Island (USAPI) jurisdictions.
- Many policies, procedures and training sessions need to be developed and conducted in each jurisdiction so that the required information gets reported to the jurisdiction cancer registries. The CDC, University of Hawaii and eventually the University of Guam/Guam Cancer Registry will help each jurisdiction develop appropriate policies, procedures, provide resources and conduct training.
- The emphasis of the next 3-4 years will be to develop jurisdiction-specific and regional reporting policies, to create robust medical records systems, to utilize standard coding systems in clinical care, to develop methods of systematic data collection, and to develop methods of accurate cancer diagnosis and staging.

Who sees and uses the jurisdiction Registry data?

- Each jurisdiction's DOH/MOH will be responsible for maintaining the Abstract Plus database. UH is working with the CDC to develop some simple reports from Abstract Plus. These reports will include the numbers and types of cancer cases, sorted by municipality/village or by ethnicity. This preliminary information will be enough to help guide short-term planning and implementation of various health programs in each jurisdiction. When new or updated information is available from the Pacific Regional Central Cancer Registry, that information will be reported back to the jurisdictions.
- The Regional Cancer Registry will be responsible for making annual reports to the CDC National Program of Cancer Registries (NPCR). An annual US Cancer Statistics report is generated from this and additional information from the National Cancer Institute's SEER Registries. Information from the US Cancer Statistics is also shared to produce the Cancer in North America report. This

information is also periodically shared internationally to produce a variety of international cancer reports. All of this information is used to form the basis and justify the need for policy, funding, program and research development.

- The jurisdiction registries should be providing their Cancer Program with annual information to help guide the implementation of the comprehensive cancer control plan.
- Periodically, researchers, other US Federal or international agencies may request information about the cancer burden in each country and the region. For jurisdiction data, each Secretary/Minister/Director of Health needs to approve the release of data. In the case of researchers, each jurisdiction should review the research proposal to ensure that the research is sound and justified. If an inquiry is made for Pacific Regional Data, the request must be approved by the PRCCR Advisory Committee (the Cancer Council of the Pacific Islands [CCPI]).

Will other jurisdictions be able to “see” our Registry data?

- Not the individual abstracts. When any Cancer Registry produces reports, the individual names are not released. Only the aggregated, de-identified data is released in the reports.

How much does a cancer registry cost and who funds it?

- There are several types of cost associated with a cancer registry
 - Personnel
 - Cancer registrar / registry data specialist (**1.0 FTE funded by UH subcontract, 6/30/07-6/29/2012**)
 - Medical records, laboratory, physicians and other health workers who understand and can do the required job responsibilities
 - Supplies, equipment and telecommunications
 - Fax, copier, scanner
 - Desktop or laptop computer and printer
 - Phone/fax/internet
 - Books or resource materials (**UH providing**)
 - Online training courses (**UH may provide**)
 - Travel
 - For training and other educational conferences (**travel to 1 week-long regional registry meeting/training funded by UH subcontract**)