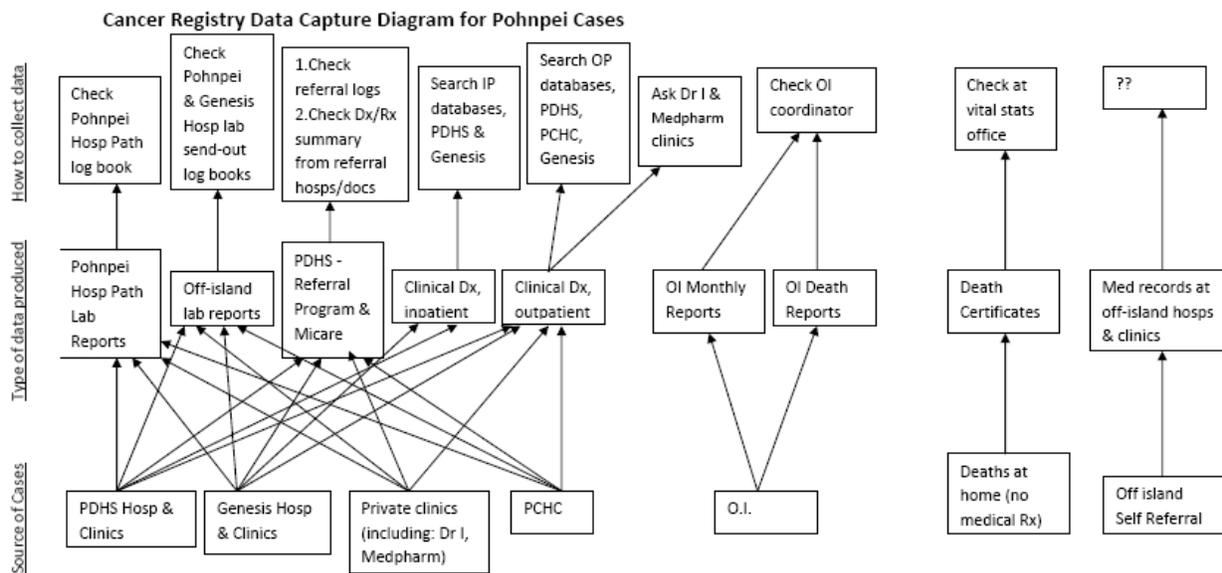


Annex B: Example From Pohnpei State of QA Approach to Assure Cancer Registry Data Completeness

I. Data Sources for Cancer Registry:

It is very challenging to assemble a complete registry of cancer cases because cases come to attention in a variety of ways in Pohnpei. Some patients in the outer islands, for example, may have obvious tumors but may never travel to Pohnpei proper for medical tests. Other patients may be referred or self-refer to a variety of doctors and hospitals abroad where they may be diagnosed with cancer. The data map below (Figure 1) shows the various sources of cancer case data (along the bottom of the diagram), the various forms in which the data might be found (along the middle of the diagram) and the ways in which the data might be captured (along the top of the diagram). Following the data map is a proposed procedure that might be followed by cancer program personnel to capture the data as efficiently and completely as possible.

Figure 1: Data Map, Pohnpei Cancer Cases



Abbreviations: PDHS= Pohnpei Dept of Health Services; PCHC= Pohnpei Community Health Center; Dr I and Medpharm= private physician practices in Pohnpei; IP=inpatient; OP=outpatient; OI=outer islands; Dx= diagnosis; Rx= treatment.

II. Cancer Registry Data Harvest Procedure:

The usefulness of the registry depends upon getting accurate, up-to-date information into the database. This information must be collected from a variety of sources because cancer in Pohnpei people is detected in a variety of ways and in a variety of different places. In addition to finding cancer patients to

enter into the registry, information about their work-up, treatment, disease progression and survival must be entered into the database on an ongoing basis as this information becomes available.

To find new cases to enter into the registry:

Monthly:

1. Check Pohnpei Hospital Pathology log book results from the past month looking for any “tumor”, “cancer”, “carcinoma”, “neoplasm”, “sarcoma”, “malignant/malignancy”, “leukemia” or “lymphoma” results. If Genesis Hospital develops an in-house pathology service then the pathology log book there would also need to be checked.
2. Check the off-island lab send-out log books in Pohnpei Hospital for the past 2 months. Check results for all send-out biopsy specimens, cytology slides and blood smears to find any cancer-related results as above.
3. Check Pohnpei DHS medical referral office for all referrals for the past month, looking for any cancer-related diagnoses or uncertain diagnoses (sometimes these are symptoms like weight loss or abdominal pain of uncertain cause). Enter these names and chart numbers onto your “possible cancer case worksheet” for further investigation.
4. Search inpatient database both at Pohnpei Hospital and Genesis Hospital for past month for ICD Codes #..... to
(obtain guidance from the Guam or Hawaii Tumor Registry for recommended ICD Codes- these must be consistent across jurisdictions so that the regional database is useful)
5. Search outpatient databases at PDHS, PCHC and Genesis clinic for past month for same ICD Codes.
6. Phone call to Dr I, Medpharm Clinic, and any other private medical clinics in Pohnpei to ask for any new or suspected new cancer diagnoses.
7. Phone call to OI Coordinator to ask for any new suspected tumor/cancer cases and for any suspicious deaths in the OI that may have been from cancer.
8. Check Vital Statistics office and review all deaths from past month for possible cancer cases.

Steps 1-8 above will give you a list of possible new cancer cases. Use steps 10 and 11 below for adding patients to the registry.

9. Investigate possible cancer cases from steps 1-9 above by reviewing charts, contacting patients’ doctors/health assistant, and collecting off-island records for review to determine which patients do have a cancer diagnosis.
 - a. Once a case patient’s initial work-up is complete¹ (patient’s diagnosis and staging are complete- i.e. all planned biopsy results, imaging studies and consultations have been obtained) enter patients with a definite cancer diagnosis into the registry and cross off their name from the “possible case” worksheet list (see Figure 2).
 - b. Cross patients with a definite non-cancer diagnosis off the “possible case” worksheet.

¹ Cancer program physician will often need to be consulted to decide when work-up is complete and case is ready to enter into registry

- c. Leave patients who still are uncertain on the “possible case” list.
10. It will take time for some of these cases (especially those referred off-island) to collect enough information to decide whether they are a cancer case. Each month repeat step 10 above for all of the uncertain cases from the past 12 months.

To follow-up on old cases in the registry:

Yearly (in January):

1. For each active registry case contact patient and his/her physician(s), both on-island and off-island (and death certificate if deceased) to obtain the following information for updating cases in the registry: ²
 - a. Survival (and cause of death if deceased)
 - b. Reports of recurrence or progression of the patient’s original cancer (get information from patient, family, treating doctors or health assistant)
 - c. Reports of any new cancers
 - d. Additional cancer treatment(s) since last data entry

Figure 2: Sample Cancer Registry “Possible Case” worksheet:

Month: _____ RMI Cancer Registry: “Possible Case” Worksheet

Name	DOB (m/d/y)	Chart #	Sex	Source*	Chart/Record Review Date(s)	Comments	Decision C=case N=non-case	Date Entered to Registry	Date Deleted
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									
11									
12									
13									
14									
15									
16									
17									
18									
19									
20									
21									
22									
23									

*Source: LSO=Lab send-out logbook; MPR=Majuro Hosp Path Report; OP=outpatient database; OP(E)=Ebeye outpatient database; IP=inpatient database; IP(E)=Ebeye inpatient; OI=outer island report; DC=death certificate; Ref=referral log book; 177=177 program database

**Decision date – this is the date that case is decided as a cancer case (for entry into registry) or a non-case

² To contact patients and physicians use form letters provided by the Hawaii Cancer Registry (and translated into both English and local languages), phone calls, and visits as needed.

III. QA Indicators to Assure Complete Collection of Data for Cancer Registry:

The following items could be used to assure completeness of data collection (Figure 3).

Figure 3: Sample indicators for QA survey of cancer registry data collection

Public Health	QUALITY ASSURANCE SURVEY					
CANCER REGISTRY						
(Note: ● = item for direct observation, ► = item with special instructions)						
Standard	Cancer Registry Data is Complete and Accurate					
Survey ITEM	Y	N	PROBLEM	CORRECTIVE ACTION TO BE TAKEN	BY WHOM	BY WHEN
<i>Services</i>						
1 ● Program manager/staff have a calendar schedule for monthly checks of all registry data sources						
2 ● Schedule has sign-off boxes showing that all potential data sources were contacted during the most recent month.						
3. ● All new possible cancer cases have been entered into the "Possible Case Worksheet"						
4 ● "Possible Case Worksheets" from past 12 months have all been updated in most recent month (with confirmed new cases entered into the cancer registry.						
5. ● Cancer registry shows that all existing cases have been up-dated for new information in January of the current year.						