February, 2009

Discussion Paper for Use of Quality Assurance to Support Comprehensive Cancer Control Activities in PIHOA Jurisdictions[1]

Introduction:

Quality Assurance (QA) consists of the setting of explicit standards for health care activities, the use of measurable indicators to judge whether standards are being met, and the use of indicator data to take action to improve performance. Both PIHOA and the Cancer Council of the Pacific Islands have recognized the opportunity for linking the PIHOA QA Initiative, which seeks to assist the public sector health departments of member jurisdictions in building QA systems, with the programs in the region that are under the umbrella of the Cancer Council (including Comprehensive Cancer Control, the Cancer Registry project and the Center of Excellence in Eliminating Disparities (CEED)). Under the auspices of the Cancer Council, each of the six PIHOA jurisdictions has established a cancer coalition and program secretariat and formulated a comprehensive cancer control plan. The objectives and activities laid out in the plans have much in common with one another, though they are customized to each jurisdiction. They all include items in several domains: encouraging community collaboration, increasing awareness of cancer burden, risk factors, and preventive measures, improving cancer and risk factor surveillance, improving the reach of cancer screening activities, improving clinical cancer management capacity, and improving the standard of palliative cancer care. Building QA for cancer control starts with recognition of what constitutes excellence within these domains. One way to approach this is to imagine what an ideal system would look like from the point of view of the people (including both those with and without cancer) living in a jurisdiction.

- Key information about cancer (including its nature, recognition, prevention, and treatment) would be widely available in forms that are easy to understand.
- Preventive services (e.g. tobacco and alcohol cessation services, screening, and vaccination) would be widely accessible and delivered in a comfortable, convenient, low stress manner.
- Patients would feel that providers respect them, listen to them, and advocate for them.
- Patients would have a clear understanding of their diagnosis and treatment options and be full participants in the process of care

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- Patients would have confidence that their medical care providers are up-to-date and providing sound advice regarding management and treatment.
- Needed materials, supplies and equipment would be readily and consistently available.
- Families would be assured of receiving the information and support they need to care for their loved ones with cancer
- Policy makers would have a clear understanding of policy options that can decrease the burden of cancer in the community

Cancer QA Program Design Considerations:

In designing a QA program to support the cancer control activities in the region, there are several important considerations:

- While it is desirable to include QA components that improve performance over the whole range of program activities, QA activities themselves carry a burden of paperwork and regulation. Therefore, it is important to strike a balance between simplicity and comprehensiveness when designing a QA program.

- QA programs may either focus on outcomes on the one hand, or inputs and processes on the other. Outcomes relate especially to major goals of the cancer coalitions (to effect healthier lifestyle choices, to detect cancers at earlier stages, to reduce the cancer burden, to improve the treatment and quality of life for cancer patients, and to improve cancer data collection). The Cancer Council of the Pacific Islands has formulated a set of Minimum Regional Indicators consisting of the following cancer-related outcomes that will be useful for tracking the impact of regional cancer control activities over time:[2]
  - By 2012 each jurisdiction will achieve completed hepatitis B vaccination series in 90% of 2 year old children
  - By 2009, jurisdictions without mammography will demonstrate a 10% increase above their baseline the number of woment over 50 who are offered clinical breast exams annually
  - By 2012, each jurisdiction will demonstrate a 10% increase above their baseline the number of women age 18-65 who have a cervix who are offered cervical cancer screening at least every 3 years.
  - By 2017, each jurisdiction will demonstrate a 10% increase above their baseline the number of women 50 and older or those at high risk, who are offered a mammogram annually
  - By 2017, each jurisdiction will demonstrate a 120% increase above their baseline the number of men and women 50 and older who are offered a CDC-recommended colorectal cancer screening test.

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[2] Cancer Council of the Pacific Islands. *"Pacific Regional Comprehensive Cancer Control Plan 2007-2012"*. March, 2007. Available at: http://pacificcancer.org/Cancer/CaResources/CCC (accessed Feb. 24, 2009)

- By 2010, each jurisdiction will establish a quality assurance program for tracking cancer-related data.

These indicators will be useful for tracking the impact of regional cancer control activities over time and should be measured and reported annually for each jurisdiction's program. Note that tracking some of the items above will be straightforward (for example, information about hepatitis B vaccine completion rates for 2 year olds should be readily available from the immunization program reports of each jurisdiction). Others will require development of a methodology for measurement (for example, measuring colorectal screening rates could be done using lab records, procedure room log books and/or chart reviews. Consideration will need to be given regarding whether and how to capture information from private sector medical providers).

- While outcome-oriented QA indicators are useful for tracking program progress, QA activities that focus on cancer program inputs and processes (and thereby relate more to cancer program activities, rather than goals) are more useful for driving performance improvement on a day-to-day basis.
- "Whole-system" QA programs (those that cover all of the units within a health service) are currently either established or under development in Kosrae, Pohnpei, Yap, and the RMI. It is highly desirable for QA activities for cancer programs in these jurisdictions to be integrated with their whole-system QA programs. This avoids confusion, provides a ready-made way to institutionalize cancer QA activities and should be less expensive than maintaining separate local QA structures.
- Whether or not cancer QA monitoring activities are integrated into larger QA programs, **it is essential that quality monitoring be linked to a process for improving performance**. The whole-system QA programs in the jurisdictions cited above do have such built-in provisions for taking action. Stand-alone QA programs for cancer will need to have a clear process specified so that QA reports will be used to make needed program changes.
- Some QA activities may only be feasible to conduct on a regional basis. For example, quality control for diagnostic coding may require expertise that is not available or easily installed at the local level in most jurisdictions.
- Agreeing on a regional "core set" of QA indicators for cancer programs is desirable, since this would allow sharing of QA program components, and avoid duplication of effort.
- Though much of a QA program for cancer control could be designed regionally, some customization will be needed to reflect differences in objectives and activities among the jurisdictions.

Options for QA Indicators:

The following section outlines some of the ways that performance for a variety of cancer program objectives can be measured.

Counseling services:

- Sections of the plans call for the identification or development of training modules for counseling services. These include modules for informing the public regarding the dangers of tobacco, dietary factors that cause cancer and ways to modify diets, role of obesity in cancer and the benefits of physical activity, techniques for tobacco cessation, the importance of HPV and Hepatitis B vaccination, cancer early warning signs and symptoms, and the importance of screening for certain cancers. There is also a plan to deliver training to family caregivers regarding proper supportive treatment of patients with cancer. Quality of these services can be measured by:

    - Counselor certification: Once the key messages and rubric for delivery of these messages are developed, staff or community members who are selected to execute these programs can be tested for competency using a checklist that verifies that all steps of the intervention have been performed, and that the all of the key messages have all been satisfactorily delivered. A standard can be set (and regularly verified by the QA surveyor) that all people delivering the intervention for the program should be certified using this system once every year for each module that they will deliver. Local health professions faculty or senior health department staff can be used to perform the certifications. An example of a certification worksheet for cancer-related client counseling can be seen in **Annex A** below. The plans also call for educational and motivational interventions to be delivered to groups (e.g. in schools, villages or churches). The same process of defining a recommended approach to such encounters and the key messages to be delivered can be done for groups as for individual counseling. Those who will deliver the sessions can also be certified for these tasks as above.
    - Testing for client learning: Another way to measure the quality of education interventions is by testing recipients for understanding of key messages. This can be done both for individual and group educational sessions. To do this, a “key messages test” would need to be developed and translated into appropriate language(s), and a standard way to administer it would have to be defined (e.g. it could be given verbally by a QA surveyor wherever the educational session is held). A standard can be set (and regularly verified by the QA surveyor) for the process and results (e.g. the test is administered to assess the performance of a particular counselor to at least 10 members of a target audience for each module that the counselor is using once each year, with an average test score of at least 70%). It is logistically a lot more difficult to measure quality of these interventions using client testing than it is by using counselor certification.

Palliative care:

- A standard can be set (and regularly verified by the QA surveyor) that a defined set of palliative care medications should all be kept in stock (e.g. morphine, methadone, ibuprofen, promethazine suppositories, acetaminophen, milk of magnesia).
- A standard can be set (and regularly verified by the QA surveyor) that all active cancer patients, at home and in hospital, must have a symptom control assessment and individualized plan for palliation renewed once each month.

- Technical competency certification could also be developed to assure that symptom control assessment and palliative care planning is being done competently by whichever health workers are designated to perform this function in the jurisdiction. A standard could be set (and regularly verified by the QA surveyor) to require explicit identification and certification of personnel who perform this duty.

Clinical performance:

- The quality of care delivered by health care providers can be measured by setting appropriateness criteria for such areas as performance of recommended cancer screening activities in the primary care setting, the performance of tobacco cessation counseling for users according to a defined protocol, and the completeness of assessment and counseling for patients diagnosed with cancer. Standards could be set (and regularly verified by the QA surveyor) regarding the percent of encounters in various settings that fully meet criteria. This type of QA is quite time-intensive, and is often done through clinical chart review. Some appropriateness criteria can also be measured by post-encouter patient surveys, which also can be used to measure effectiveness of provider-patient communication and client satisfaction.

Cancer screening activities and preventive vaccination:

- Technical competency certification can be developed for such activities as taking and handling pap smears (for jurisdictions that are doing cervical cytology for screening) or for visual inspection with acetic acid (VIA; for jurisdictions that are using this for cervical cancer screening). Testing for pap smear competency could be done via in-person observation by an expert. Conceivably, labs performing cytology could also track the percentage of technically inadequate smears for each health care provider who performs them. A standard could be set (and regularly verified by the QA surveyor) requiring re-training of any provider having a higher percentage of unsatisfactory smears.
  VIA competency testing could be done using written test to verify knowledge of proper procedure combined with identification of lesions visually using photographs. A standard could be set (and regularly verified by the QA surveyor) to require explicit identification and certification of personnel who perform this duty.
- Outreach to target populations for such activities as HPV vaccination of adolescent girls and cervical cancer screening for women in high risk age group (e.g. 30-50 years) can be assured by setting a standard to require functional HPV and cervical cancer screening registries listing all individuals in the target groups in the jurisdiction. A QA surveyor can regularly verify that such registries are functional by checking that entries are up-to-date, that clients who are overdue for the intervention can be readily identified within the registry, and that documentation exists showing that outreach attempts have been made within the past 3 months for all overdue clients.

Lab activities:

- Standard lab QA procedures, including systems to assure maintenance of testing equipment, calibration of equipment, proper identification, tracking and handling of specimens, adherence to testing protocols and external proficiency testing of technicians can all be applied for cancer-related lab tests. For examples of QA surveys that support such standards see the PIHOA Generic QA Survey for lab (at http://new.pihoa.org/initiatives/qa.php) or the WHO Assessment Tool for Laboratory Services (at http://www.who.int/management/facility/laboratory/ATLASAssessmentToolLaboratoryServices.pdf)

Involvement of Community Stakeholders

- The involvement of coalition members from various sectors of the community in each jurisdiction is an important component of each plan. A "stakeholder satisfaction survey" can be developed to obtain feedback about the vitality of the coalitions. A standard could be set (and regularly verified by the QA surveyor) requiring the yearly performance of this survey with all coalition members, and specifying a passing average survey score.

Functional cancer registries:

One of the greatest challenges that the cancer programs at the local and regional levels will face is that of improving cancer data collection systems. Improving the quality of cancer registries is also the area that a QA program may be most helpful. The following are some of the QA indicators, that can be verified regularly by a QA surveyor and that may be useful:

- Registry computers are password protected.
- File contains signed confidentiality statements, from all cancer program staff.
- Documentation shows completion of local cancer data transfer to the regional registry in the past 3 months.
- Technical competency certification for medical records staff and physicians could be developed with regard to cancer diagnosis classification and coding, based on training modules from the Centers for Disease Control and Prevention, and the North American Association of Central Cancer Registries. A standard could be set to require completion of the modules and/or passage of a competency exam by staff identified as responsible for cancer diagnostic classification and coding.
- Accurate data extraction, classification and coding could also be done by expert chart reviews, with a standard set for accuracy and completion rates. For most of the jurisdictions, this QA activity would require the involvement of outside experts.
- Completeness of local registry data can be promoted by assuring regular data harvesting from all relevant cancer data sources, and regular updating of information for established registry cases. An example from the RMI of a data source map, data harvest procedure and quality assurance matrix to assure registry completeness is shown in Annex B.

Hewitt M and Simone V. National Cancer Policy Board, Institute of Medicine and Commission on Life Sciences, National Research Council. National Academy Press, Washington, D.C. 1999.
"Ensuring Quality Cancer Care", a book published by the Institute of Medicine, is the most exhaustive reference about QA measures suitable for cancer control programs (though most of the discussion focuses on this topic in a U.S. context). Especially see Chapter 6- Cancer Care and Quality Assurance. [3]

[3] Available at: http://www.nap.edu/catalog.php?record_id=6467#toc (accessed Feb. 24, 2009)

Annex A: Sample Task Certification Worksheet for Cancer-Related Client Counseling

Task Certification: Client Cancer Awareness Counseling Session

Rating: 1- Poor
2- Needs Improvement
3- Average (passing)
4- Good
5- Excellent

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CHW Name

When doing cancer awareness session you should:	Done	Not Done	Rating	Comments
1. Introduce yourself and tell why your are visiting				
2. Use language that people can understand best. Get translator if needed.				
3. Help client(s) to complete "Cancer Risk Assessment" sheet				
4. Score Cancer Risk Assessment for each client, classify them as "High", "Medium" or "Low" risk for cancer				
5. Notify client(s) of the types of cancer screening recommended them based on their Cancer Risk Assessment				
5. Review Cancer Early Detection flipchart with patient/family:				
a. Explain the purpose of the flipchart (to help patient and family to understand what cancer is, how cancer can be detected, and how to prevent harm to the patient and family from cancer).				
b. Position yourself so that patient/family can see flipchart, and you can see notes on back.				
c. Show and explain each page of flipchart, translating as needed and checking for patient/family questions before going to each new page.				
d. At end of flipchart ask if there are any other questions. (Give explanations or agree to find answers for the client(s) or refer them to a health care provider)				
6. Review "Cancer Signs & Screening" sheet with patient/family and leave it with them				
7. Refer client to screening clinic (Indicate whether and when patient agrees to come:)				

Sign when health worker is certified for this task*:

____________________ _____________
Instructor sign Date

**Notes:*

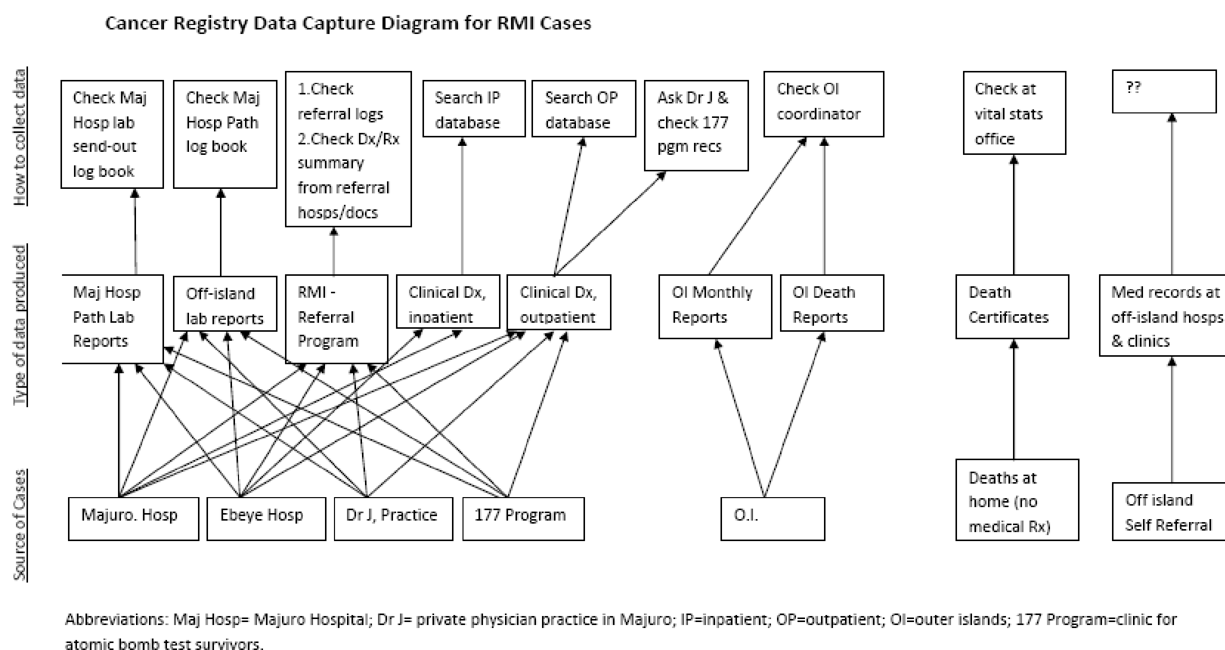
1. *To be certified,* ***all*** *items must be rated 3 or above.*
2. *Certification must be renewed each year for each task*
3. *File certification forms with Cancer Program Manager*

Annex B: Example From RMI 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 the RMI. Some patients in the outer islands, for example, may have obvious tumors but may never travel to Majuro or Ebeye 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, RMI cancer cases



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 RMI 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 Majuro Hospital Pathology log book results from the past month looking for any "cancer", "carcinoma", "neoplasm", "sarcoma", "malignant/malignancy", "leukemia" or "lymphoma" results.
2. Check the off-island lab send-out log books in Majuro 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 RMI 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 for past month for ICD Codes #........... to …………. *(obtain guidance from the Hawaii Tumor Registry for recommended ICD Codes- these must be consistent across jurisdictions so that the regional database is useful)*
5. Search outpatient database for past month for same ICD Codes.
6. Search 177 program outpatient database for same ICD Codes.
7. Phone call to Dr J (private medical practice in Majuro) to ask for any new or suspected new cancer diagnoses.
8. 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.
9. Check Vital Statistics office and review all deaths from past month for possible cancer cases.

Steps 1-9 above will give you a list of possible new cancer cases. Use steps 10 and 11 below for adding patients to the registry.

10. 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 complete[4] (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.
    c. Leave patients who still are uncertain on the "possible case" list.

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

11. 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: [5]

    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									
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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

[5] To contact patients and physicians use form letters provided by the Hawaii Cancer Registry (and translated into both English and Marshallese), 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

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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
Services						
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.						