DETERMINING CANCER BURDEN IN RESOURCE LIMITED SETTINGS:
Role of the Pacific Regional Central Cancer Registry (PRCCCR) Advisory Committee

2009 National Program of Cancer Registries Program Director Meeting
April 15, 2009

Lee Buenconsejo-Lum, MD
DEPARTMENT OF FAMILY MEDICINE AND COMMUNITY HEALTH
JOHN A. BURNS SCHOOL OF MEDICINE
UNIVERSITY OF HAWAII
USAPIN
WHAT/WHERE

**United States**
- Guam

**Affiliated States**
- American Samoa
- Commonwealth of the Northern Mariana Islands (CNMI)

**Pacific Island Nations**
- Federated States of Micronesia (FSM)
- Republic of the Marshall Islands (RMI)
- Republic of Palau

**Flag Territories and Commonwealth**
460,000 people in over 2 million square miles of Pacific Ocean
Challenged infrastructure and capacity
Off-island referrals or on-island deaths from unconfirmed cases
GEOGRAPHICALLY DISPERSED

• Global Geography
  - 14 time zones between Wash DC and Palau (-0500 to +0900 UTC/GMT)
  - Satellite

• Pacific Geography
  - International Date line
  - $3,000 round trip Yap to Hawaii
  - $900 round trip Hawaii to Wash DC

• Island Nation Geography
  - Logistics to get within island nations
  - Boats
11 hour flight from Palau to Honolulu

13+ hour flight from Honolulu to the East Coast

5.5 hour flight from American Samoa to Honolulu
HISTORY

1997 - PIHOA (Guam) and PBMA (YAP)
1999 - Evaluation of CA in the USAPI, Nauru and Kiribati
2000 - ICC amends mission statement
2001 - NCI - Center to Reduce Cancer Health Disparities
   USAPI Assessments 2002
2002-03 - PBMA 2003 - Regionalization
   Cancer Council of the Pacific Islands (CCPI)
2004 - CDC Comp Cancer 2004
   Community-Coalitions
2005 - CDC funded Cancer Registry Assessment
2006-07 – Building partnerships, buy-in, setting basic policies
2007 July – Received NPCR funding for PRCCR
PRE-PACIFIC CANCER INITIATIVE

- access
- awareness
- screening

- diagnosis
- treatment
- Palliative care
CANCER COUNCIL OF THE PACIFIC ISLANDS
CCPI = ADVISORY COMMITTEE FOR PRCCR
Why a cancer registry?

• No functional cancer registries in the USAPI prior to 1997
• Data repositories (breast and cervical cancer, other databases) present, but are not cancer registries
• Need for uniformity in reporting, quality data, ability to compare data and use it meaningfully
Registry needs assessments

- 1995 Mike O’Leary: Health Data in Micronesia
- 1999 NCT cancer in Micronesia (RMI, Nauru, Kiribati)
- 2002 NCI assessments
  - Baseline structure, function, operations
- 2005 CDC (CCC) assessment
  - Details: diagnostic and treatment capacity, ICD9/10, reporting sources, data flow, needs, “what should a registry look like?”
<table>
<thead>
<tr>
<th>PROGRAM OR SERVICE</th>
<th>American Samoa</th>
<th>CNMI</th>
<th>Guam</th>
<th>FSM</th>
<th>Palau</th>
<th>RMI</th>
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</thead>
<tbody>
<tr>
<td><strong>CANCER SCREENING</strong></td>
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<tr>
<td>BCCEDP</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Mammography</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Pap Smears</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>limited, none on outer islands</td>
<td>Yes</td>
</tr>
<tr>
<td>On-island processing of pap smears</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Colorectal cancer screening (FOBT)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Prostate cancer screening</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
<td>Pohnpei only</td>
<td>Yes</td>
<td>Yes</td>
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</table>
## Situational Assessment - 2007

<table>
<thead>
<tr>
<th>Service</th>
<th>American Samoa</th>
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</thead>
<tbody>
<tr>
<td><strong>CANCER DIAGNOSIS AND TREATMENT</strong></td>
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<tr>
<td>On-island chemotherapy</td>
<td>Yes (maintenance)</td>
<td></td>
<td>Yes</td>
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<tr>
<td>On-island radiation therapy</td>
<td></td>
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<tr>
<td>Off-island referral to Philippines for diagnosis / treatment</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Off-island referral to Hawaii for diagnosis / treatment</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Off-island referral to New Zealand for diagnosis / treatment</td>
<td>Yes</td>
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<tr>
<td>Off-island referral to U.S. Mainland for diagnosis / treatment</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
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<tr>
<td>Program or service</td>
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<tr>
<td>Philippines hospitals</td>
<td></td>
<td>X</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<td>Hawaii labs and hospitals</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>x</td>
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<tr>
<td>New Zealand hospitals</td>
<td></td>
<td>X</td>
<td>X</td>
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<tr>
<td>US Mainland labs and hospitals</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>Local National (or FSM State) hospital</td>
<td></td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 per State</td>
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<tr>
<td>Military hospital</td>
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<tr>
<td>VA outpatient clinic</td>
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<td>Private hospital</td>
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<td>1</td>
</tr>
<tr>
<td>Private physicians and clinics</td>
<td>less than 5</td>
<td>many</td>
<td>many</td>
<td>less than 5</td>
<td>less than 5</td>
<td>less than 5</td>
</tr>
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</thead>
<tbody>
<tr>
<td><strong>DATA</strong></td>
<td></td>
<td></td>
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<tr>
<td>ICD-10 coding for deaths</td>
<td>(X)</td>
<td>(X)</td>
<td>X sent to NCHS</td>
<td>X coded at FSM Natl</td>
<td>(X)</td>
<td>(X)</td>
</tr>
<tr>
<td>ICD-9 for hospital discharges</td>
<td>(X)</td>
<td>(X)</td>
<td>(X)</td>
<td></td>
<td></td>
<td>(X)</td>
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<tr>
<td>Cancer Database</td>
<td>Cancer mortality registry, BCCEDP</td>
<td>None</td>
<td>Abstract Plus, reports to SEER</td>
<td>Varies (EpiInfo, Excel, paper)</td>
<td>Registry Plus, EpiInfo, BCCEDP</td>
<td>Excel, Nuclear Claims Tribunal</td>
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<tr>
<td><strong>REGISTRY-SPECIFIC</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Cancer Registry</td>
<td></td>
<td></td>
<td>UOG / HTR Registry Plus</td>
<td>NPCR</td>
<td></td>
<td>RMI National registry</td>
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<tr>
<td>Law authorizing reporting to CCR</td>
<td>(X)</td>
<td>(X)</td>
<td>Legislation Introduced 1/07</td>
<td>(X)</td>
<td></td>
<td></td>
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<tr>
<td>Formal Policies and procedures</td>
<td></td>
<td></td>
<td>(X)</td>
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</table>
Formation of the Partnerships

• **CDC NPCR** wanted to better understand the issues, potential for partnerships with University of Guam (UoG) Guam Cancer Registry (GCR)
  – GCR supported by **NCI U56 (MI/CCP)** mechanism through 12/09

• Determined strengths and weaknesses of present registries and processes
 IMPLEMENTATION OF THE PACIFIC REGIONAL CCC PLAN

PIHOA (overarching Advisory)

CCPI (overarching Mgmt)

University of Hawaii Dept. of Family Medicine (administrative, technical assistance)

Regional Cancer Registry

Hawaii Tumor Registry & Cancer Research Center of Hawaii (technical assistance)
Appointed PH + Clinical Rep
- Usually high in management structure
- Can influence policy and programs

Senior-most health official
- Main policy maker
- Local and regional focus
- QA, Data Quality and HRH initiatives

09-18-07 Regional Registry
Operating Framework

• Jurisdictions **own and control** data
  – Public health planning and evaluation
  – Proportional rates
  – Co-morbidity and risk factor information
  – Local reports needed for FAS reporting to World Health Organization (Millennium Development Goals), CoFA oversight committees

• Central registry ensures data is of good quality

• Consolidated case sent back to the jurisdictions, but the responsibility for reporting to NPCR is with the Central Registry
Advisory Committee

• CCPI – meets twice yearly
• Framework, buy-in, engaging partners – since November 2005
• Obtain and maintain PIHOA support
  – they designated UH as bona fide agent
  – PRCCR development should synergize with PIHOA efforts
• CCPI role locally: work with CCC Coordinators, Registrars, break down barriers, follow-up on policy issues
Advisory Committee

- 2005 Nov – overarching framework
- 2006 July – made decisions that impacted the NPCR application in 3/07; incorporated Registry as Goal 4 of Regional CCC Plan
- 2006 Aug – PIHOA support for PRCCR
- 2007 Mar – Bona fide designation
  - Minister/Secretary/Director of Health
  - Attorney General
  - SIX COUNTRIES
Advisory Committee

• 2007 Aug – meeting with Advisors (HTR), workshop on death certification, identified local policy needs

• 2008 Apr – action planning on local priority items; started discussing interjurisdiction data exchange; customizing fields (co-morbidity, screening)

• 2008 Sep – troubleshooting case ascertainment, reporting

• 2009 Apr – focus on advocacy and education
3 components – year 1-2

Jurisdiction Registries and/or Databases
(Understanding of Hawaii & CDC NPCR)

- Infrastructure
  space / computer / desktop IT support (PIJ)

- Legislation

- Policies and Procedures

- Exchange Agreements

- Communication / Advocacy

- Training / Resources
  registrar / data technician / physicians / policy/decision-makers / public

- Registry-Specific Training

- Abstract Plus (software)
  customization training

Guam Cancer Registry
(HTR MI/CCP)

- Policies and Procedures

- Exchange Agreements

- Communication / Advocacy

- Training / Resources
  registrar / data technician / physicians / policy/decision-makers / public

- Central Registry-Specific Training

- Abstract Plus (software)
  customization training

Pacific Regional Central Cancer Registry
(Understanding of Hawaii & CDC NPCR)

- Infrastructure
  space / computer / desktop IT support (UOG)

- Policies and Procedures

- Exchange Agreements

- Communication / Advocacy

- Training / Resources
  registrar

- Central Registry-Specific Training

- Registry Plus Suite (software)
  customization training
Official data reporting to start in year 2 or 3

CDC National Program of Cancer Registries

University of Hawaii JABSOM Department of Family Medicine (Palatox) (Buenconsejo-Lum)

Pacific Regional Central Cancer Registry (housed in Guam)

American Samoa Cancer Registry (DHS)
CNMI Cancer Registry (DPHES)
FSM Cancer Registry (DOH)
Palau Cancer Registry (MOH)
RMI Cancer Registry (MOH)
Guam Cancer Registry (UOG)

Chuuk DHS
Kosrae DHS
Pohnpei DHS
Yap DHS
Ebeye Hospital

CCPI (Advisory Committee)
FIHOA (Overarching Advisory)

Technical Assistance
Hawaii Tumor Registry
Tricia Torris, Coordinator extraordinaire

Neal Palafox Professor & Chair “vision guy”

Registrars

Technical Advisors
Linda Rego & Michael Green
Guam

Commonwealth of the Northern Marianas Islands

American Samoa
THANK YOU!

• Si Yu’us Ma’ase
• Olomwaay
• Fa’a Fetai Tele Lava
• Msuulaang

• Kulo Malulap
• Komagar
• Kalangan
• Kilisou Chapur
• Kommol Tata

lbuencon@hawaii.edu
pcregistry@gmail.com