

Approaches to Collecting Cancer Incidence Data – Global Perspective

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Functions of PBCRs

- Management
- Data Collection
 - Case Finding
 - Record consolidation
 - Follow up
 - Death Clearance
- Coding
- Data Systems
- Reporting
- Sole vs Shared
- Passive – Active
- ICD-O
- Open Source – Tailored
 - **CanReg5**
 - **Registry Plus**
 - **SEER*DMS**
- Staff - Collaborate

GICR & Caribbean Hub

- **AFCRN “model”** – PI (“foreign expert”); PBCR in country; shared experience, TA & training; limited external funds
- **CARPHA “model”** – IGA plus; data center for pooled data collection and reporting, training, and building capacity
- **Latin America “model”** – Collaborative PIs (3 countries with technical leadership); PBCRs in country; self generated funds
- **Small Islands “model”** – US Associated Pacific Island jurisdictions (USAPI) collaborative approach
- **Twinning “model”** – Experienced PBCR country assists “neighbor” in registry functions

African Cancer Registry Network - AFCRN

- Virtual hub: PI, web site, 48 countries
- Members: countries with regional or national PBCR & 50% completeness based on site visits & assessments; 70% coverage in 3 years; information current on AFCRN web
- Collaborative research projects using registry data
- Data Use Agreements; de-identified data hosted at data center (IARC)
- Annual meetings, training, assessments
- Advisory Board – 4 external members
- Funding self generating through grants by PI & members

CARPHA - Caribbean Hub

- PI & staff in NCDs at CARPHA [WHO IGAs] in Trinidad & Tobago
- Technical expertise from Partners: NAACCR, NCI, CDC, IARC
- Members: CARPHA IGAs & countries in Caribbean; assessments through questionnaires and site visits, reports; country commitment to PBCRs
- CARPHA hosts de-identified data with secure country access to their data; DUAs; reporting and submission to Ci5Training (orientation to GICR, PBCRs); “mentoring”
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- Advisory Board (TBN) & Working Group
- Funding is self generating with limited funds from Partners

US Pacific Island Jurisdictions - USPIJ

- 10 island countries with about 460,000 people
- Univ Hawaii: 2004 CDC grant for Comp Ca Ctl Pgm with supplement for registry options [also 2002 NCI funded Pacific Cancer Initiative]
- Governance: UH agent for Pacific Regional Central Cancer Registry (PRCCR) with Cancer Council of the Pacific Islands (CCPI) as Advisory Board; Univ Guam hosts operational office with a Central Registrar
- Each Pacific Island Jurisdiction (PIJ) is a small central registry; use Abs Plus, Web Plus and Registry Plus; edits and processing occurs at PIJ and UG; tabular reports are generated & used for cancer control and outreach
- Distance education sessions and annual registry training

“Twinning” Model

- Formal and structured bi-lateral relationship between two country with goal: an established PBCR and development of a new PBCR
- Agreement (plan, timeline, authority for “shared” data collection); may be a “contract” relationship or development of capacity for new PBCR
- Goal of having at least two years of PBCR data for submission and use in reporting cancer rates for countries which previously had no data
- Active participation in a regional Hub; shared knowledge of registry operations, management, reporting & use of data
- May be a subset of activities within a regional Hub; self funded

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