Caribbean Hub for the Global Initiative for Cancer Registries

- Glennis Andall-Brereton
- Epidemiologist/Senior Technical Officer
  Non Communicable Diseases

Caribbean Public Health Agency (CARPHA)

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Preventing disease, promoting and protecting health
Presentation Outline

- Background
  - Cancer Registration in the Caribbean
- Challenges to Cancer Registration
- Global Initiative for Research on Cancer and the Caribbean Hub
- Opportunities
THE CARIBBEAN
CARPHA Member Countries

1 million square miles of ocean

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Member Countries:

- Anguilla,
- Antigua & Barbuda,
- Aruba,
- Bahamas,
- Barbados,
- Belize,
- Bermuda,
- BES Islands (Bonaire, Saba & St. Eustatius),
- British Virgin Islands,
- Cayman Islands,
- Curacao

- Dominica
- Grenada,
- Guyana,
- Jamaica,
- Montserrat,
- St. Kitts & Nevis,
- St. Lucia,
- St. Maarten,
- St. Vincent & the Grenadines,
- Suriname,
- Trinidad & Tobago,
- Turks & Caicos Islands

- HAITI
## Cancer Registration in the Caribbean

<table>
<thead>
<tr>
<th>Country</th>
<th>Year Started</th>
<th>Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Puerto Rico</td>
<td>1950</td>
<td>National</td>
</tr>
<tr>
<td>Jamaica</td>
<td>1959</td>
<td>Urban</td>
</tr>
<tr>
<td>Cuba</td>
<td>1964</td>
<td>National</td>
</tr>
<tr>
<td>Netherland Antilles</td>
<td>1977</td>
<td>National</td>
</tr>
<tr>
<td>Bermuda</td>
<td>1979</td>
<td>National</td>
</tr>
<tr>
<td>Martinique</td>
<td>1983</td>
<td>National</td>
</tr>
<tr>
<td>Trinidad and Tobago</td>
<td>1994</td>
<td>National</td>
</tr>
<tr>
<td>Guyana</td>
<td>2000</td>
<td>National</td>
</tr>
<tr>
<td>French Guiana</td>
<td>2005</td>
<td>National</td>
</tr>
<tr>
<td>Guadeloupe</td>
<td>2008</td>
<td>National</td>
</tr>
<tr>
<td>Barbados</td>
<td>2010</td>
<td>National</td>
</tr>
<tr>
<td>Cayman Islands</td>
<td>2010</td>
<td>National</td>
</tr>
</tbody>
</table>

Source: NCI
IARC/NCI/CARPHA

- Objectives
  - To develop a profile of registries
  - Assessment of registry practices
  - Assessment of resources (human, material and financial) available for maintaining and sustaining registries
  - Challenges facing registries
Challenges for Cancer Registration

- **Resource-challenged countries**
  - Financial, limited or no infrastructure, human resources

- **Political will**
  - Governments may change health priorities

- **Limited policies and regulation**
  - Cancer is not a notifiable disease in many Caribbean countries
  - Lack of enforcement in those few countries with this policy
  - Continued advocacy will be needed

- **Challenges in health care services needed to support cancer registration**
  - Diagnosing cancer, pathology, trained medical staff

- **Data quality, data security and confidentiality issues**
  - Lack of unique identifiers, QC/QA checks, etc.
  - Small countries, limited information technology

- **Limited collaboration and communication among national and regional stakeholders (succession planning)**

- **Limited research collaborations (local, regional, international)**
# Current state of Cancer registration in the Caribbean

<table>
<thead>
<tr>
<th>Quality of cancer registration</th>
<th>Countries</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Quality Population Based Cancer Registries (national)</td>
<td>Martinique, Puerto Rico</td>
<td>2</td>
</tr>
<tr>
<td>High Quality Population Based Cancer Registries (regional)</td>
<td>Cuba, Jamaica</td>
<td>2</td>
</tr>
<tr>
<td>Population-based registries</td>
<td>Barbados, Curacao, French Guiana, Guadeloupe, Guyana, Trinidad and Tobago</td>
<td>6</td>
</tr>
<tr>
<td>Cancer registration activity</td>
<td>Anguilla, Aruba, Bahamas, Belize, Bermuda, Cayman Islands, Dominican Republic, Haiti, Suriname</td>
<td>9</td>
</tr>
<tr>
<td>Unknown status</td>
<td>None</td>
<td>0</td>
</tr>
</tbody>
</table>
Global NCD Reporting Requirements:

- GICR formally recognized by WHO as the mechanism through which Member States are supported in efforts related to cancer targets and indicators

Global Monitoring Framework

25 indicators

Mortality & Morbidity

- Unconditional probability of dying between ages 30 and 70 years from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases
- Cancer incidence by type of cancer

Risk Factors

- Harmful use of alcohol (3)
- Low fruit and vegetable intake
- Physical inactivity (2)
- Salt intake
- Saturated fat intake
- Tobacco use (2)
- Raised blood glucose/diabetes
- Raised blood pressure
- Overweight and obesity (2)
- Raised total cholesterol

National Systems Response

- Cervical cancer screening
- Drug therapy and counseling
- Essential NCD medicines & technologies
- Hepatitis B vaccine
- Human Papilloma Virus vaccine
- Marketing to children
- Access to palliative care
- Policies to limit saturated fats and virtually eliminate trans fats
Develop capacity in low- and middle-income countries (LMICs) to produce reliable, high-quality information on the burden of cancer

- **Global network of regional hubs** to provide support and training to PBCR in defined regions

- Phased objectives with a target to provide measurable improvements in coverage and quality of cancer registries in over 20 LMICs by 2020 and a further 30 LMICs by 2025
The GICR is …

- Focused on providing data that leads to successful **CANCER CONTROL** programs
- A platform to generate and share **KNOWLEDGE** in a systematic way, using a flexible model that promotes local adoption while meeting international standards
- A commitment of leading cancer groups to work in **PARTNERSHIP** to deliver impact
Six IARC Regional Hubs for Cancer Registration in LMIC

LATIN AMERICA
Instituto Nacional del Cáncer, Buenos Aires, Argentina

CENTRAL & WESTERN ASIA AND NORTHERN AFRICA
Izmir Cancer Registry, Izmir, Turkey

SUB-SAHARAN AFRICA
African Cancer Registry Network, Oxford

CENTRAL & WESTERN ASIA AND NORTHERN AFRICA
Izmir Cancer Registry, Izmir, Turkey

SOUTHERN, EASTERN AND SOUTH-EASTERN ASIA
Tata Memorial Centre, Mumbai, India

PACIFIC ISLANDS (Planned)

Source, IARC

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IARC Regional Hubs: Core Areas of Focus

- **Training**
  - Delivery of basic and advanced courses
  - Development of accompanying resource material
- **Directed Support**
  - Site visits to review practices and provide recommendations
  - Consultancy to resolve specific issues
  - Twining programs
- **Networking**
  - Foster relationships between disciplines in cancer
  - Provide information on upcoming activities
- **Cancer Control**
  - Support cancer control interventions
  - Stimulate research of comparative studies

Source: IARC
NCI, CDC, IARC and CARPHA will lead the implementation of regional hub for the Caribbean

Close collaboration with NAACCR

Hub located at CARPHA headquarters in Port of Spain, Trinidad and Tobago

CARPHA fulfilled most of the requirements for becoming a hub under GICR:

- International standing in epidemiology research/registry collaboration
- History of collaboration with one or more GICR partners
- Facilities for training including teaching rooms, computers, office space, etc.
- Strong network and relationship with Caribbean countries
- Some staff with skill set necessary to fulfill a hub, but will require additional staff and training.
Caribbean Hub activities

Provide localized training (technical and administrative)

- Annual courses related to cancer registration
  - 1st Course – June 20-21\textsuperscript{st} (Turks and Caicos Islands)
- Ad hoc training according to specific registry requirements
- Ongoing training consultancy with registries/countries

Provision of directed and tailored support via site visits

- Review cancer registration practices and provide appropriate recommendations
- POC for registry community in the Caribbean
- Liaison between IARC and Caribbean countries
Caribbean Hub activities

Creation of networks
• Foster relationships between registries, organizations and multiple disciplines in cancer
• Establish a roster of regional cancer registry experts
• Encourage twinning between registries in the region

Stimulation of research and related studies
• Examine trends and support cancer control interventions
• Monitor trends and describe patterns in cancer burden over time
• Foster research of registration data to examine issues for cancer control
Opportunities for NAACCR Members

- To provide technical assistance to build capacity for cancer registration
  - Training
  - Mentoring
  - Twinning with Caribbean Registries

- To build partnerships
  - with Caribbean Hub
  - with countries

- Research and data supplementation
  - cancer in persons of Caribbean origin
Thank You
Muchas Gracias
Merci Beaucoup

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