

# Implementation of the Caribbean Cancer Registry Hub

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# Caribbean Cancer Registry Hub Team

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# Presentation Outline

- **Description of Caribbean region**
- Burden of cancer in the Caribbean
- History and current status of cancer registration in the Caribbean
- Regional Caribbean Cancer Registry Hub
- Relevance to cancer epidemiology in United States

# Caribbean Region

- 1, 063, 000 sq. miles
- Consists of all islands located southeast of Gulf of Mexico, east of Central America and Mexico and north of South America
- Various environments:
  - flat terrain of non-volcanic nature
  - mountain ranges
  - rain forests
  - savannah land
  - Industry
  - Mining
  - Farming, etc.



# Caribbean Population

**44 million (including population in mainland countries but excludes Puerto Rico and USVI)**

## **Diversity of ethnic/race groups**

- Afro-Caribbean
- Indo-Caribbean
- Chinese-Caribbean
- European-descent
- Native Amerindian
- Other minority populations (e.g. Syrian) and mixed descent

## **Diversity in religion**

- Christianity
- Hinduism
- Jewish, etc.

## **Diversity in languages**

- English, Spanish, French, Dutch, local creole languages

## **Differences in SES across countries and within countries**

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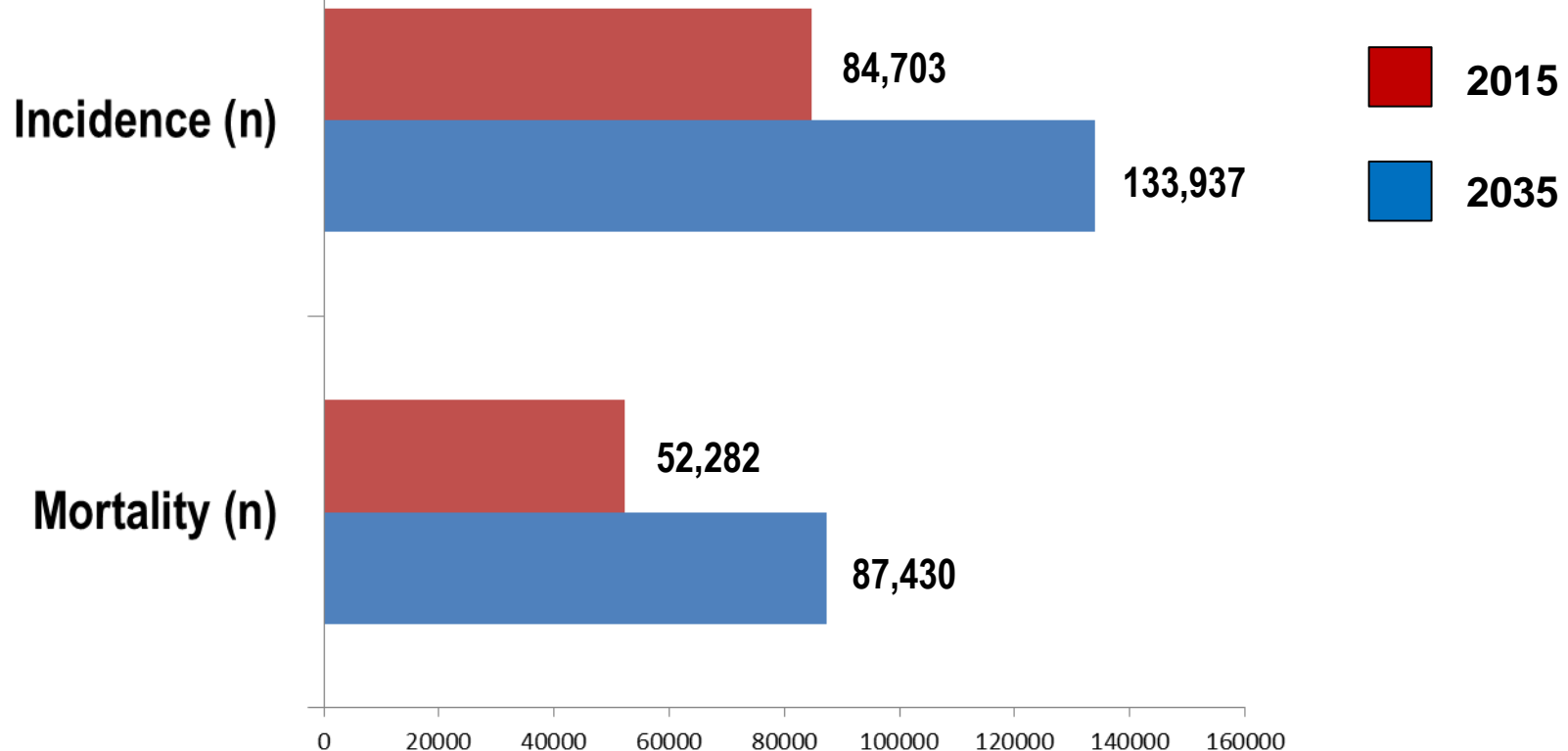
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# Cancer burden in the Caribbean

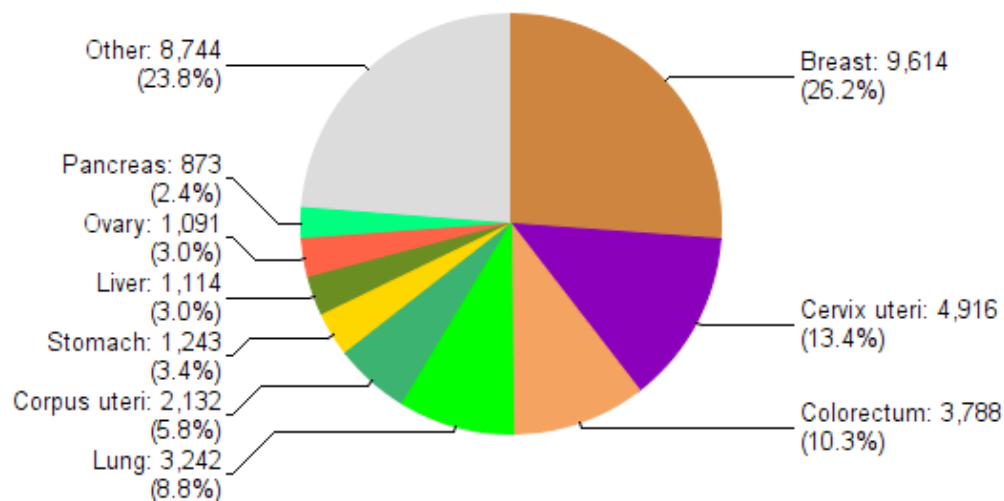
Cancer is the second leading cause of all deaths in the Caribbean

Incidence projected to increase by 58%

Mortality projected to increase by 67%

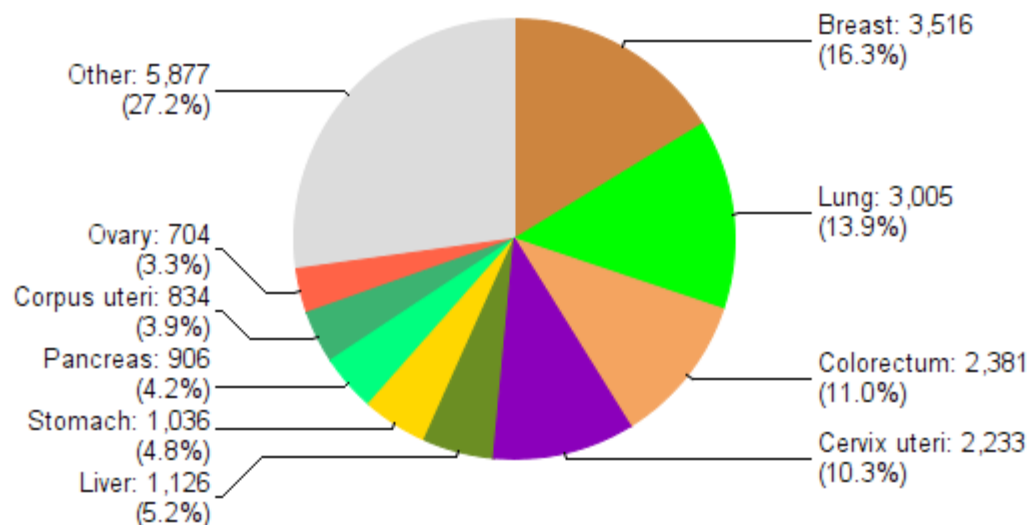


# Cancer in the Caribbean Females, 15-75 yrs.



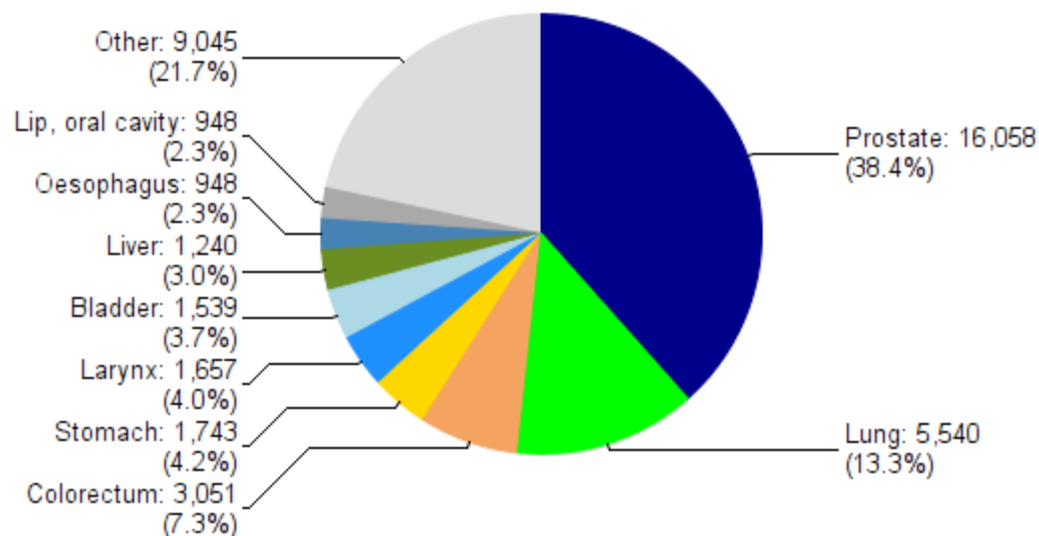
## *Incidence*

## *Mortality*



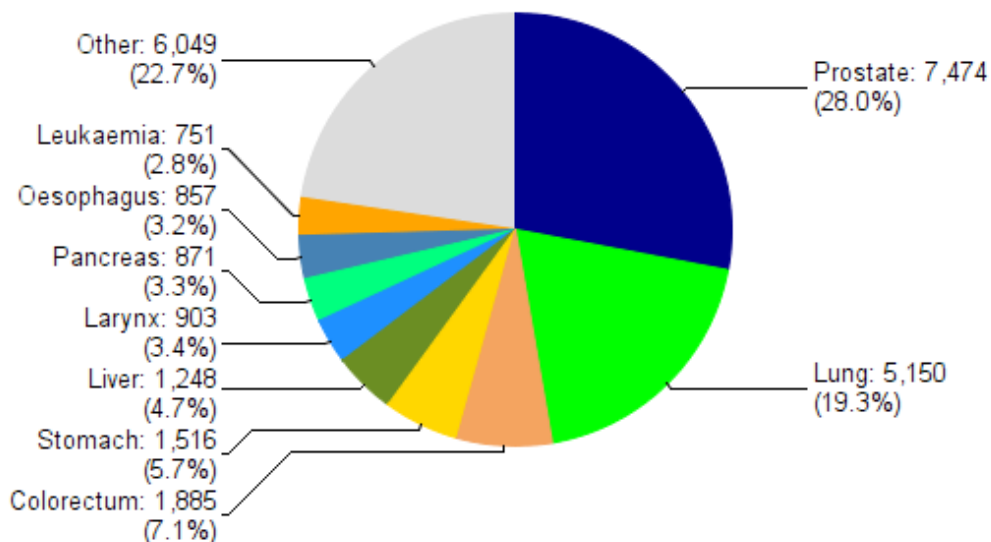


# Cancer in the Caribbean Males, 15-75 yrs.



## ***Incidence***

## ***Mortality***



***Bahamas, Barbados, Belize, Cuba, Dominican Republic, Guadeloupe, Guyana, Haiti, Jamaica, Martinique, Suriname, Trinidad and Tobago (IARC Globocan, 2012)***

# Prevalence of Cancer Risk Factors

## Modifiable:

- **Tobacco use**

- Increasing among adolescence

- **Harmful use of Alcohol**

- >4 drinks on any day for females (7.8% in British VI, 34.4% in Aruba)
- >5 drinks on any day for males (20.1% in St. Kitts, 48.6% in Aruba)

- **High prevalence of overweight and obese adults**

- Dominica:

- Overweight – 60% females, 35% males
- Obese – 30% females, 10% males

- Bahamas:

- Overweight – 80% females, 70% males
- Obese – 50% females, 40% males

# Prevalence of Cancer Risk Factors

## **Modifiable:**

- Lack of physical activity
- Less intake of fruits and vegetables

## **Host-related:**

### **Prevalence of cancer associated viruses in healthy individuals**

- HPV – 57.5% (Jamaica 70.8%)
- HBV – 9.4% (Dominican Republic 52.4%)
- HHV8 – 4.5% (Haiti 28.9%)
- HTLV – 1% (Dominica 12%)

## **Genetics**

- High prevalence of BRCA1 mutations among Bahamian breast cancer patients (23%), higher in women diagnosed before age 50 (33%). Believed to be a founder mutations.

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# History of Cancer Registration in the Caribbean

## Recognition of a need for cancer registries:

- **1970s:** Establishment of hospital-based registries by hospital personnel (unofficial hospital-based registries)

## Efforts to improve cancer registration:

- **1981:** PAHO sponsored a seminar on hospital-based registration
- **1980s:** Attempts made to create official hospital-based registries using CANREG, but efforts abandoned due to lack of resources
- **1990:** Cervical cancer prevention and control initiated by Caribbean Cooperation in Health which was coordinated by PAHO, OPEC and Caribbean Program Coordination Center. During this time, it was determined that health information system was needed
- **1991:** PAHO supported training in death certification and offered assistance to establish cancer registries in Anguilla, Antigua and Barbuda, British Virgin Islands, Dominica, Grenada, Montserrat, St Kitts and Nevis, St. Lucia and St Vincent and the Grenadines

# History of Cancer Registration in the Caribbean

## Ongoing activities for cancer registry strengthening:

- **1994:** Workshop for cancer registration held at the University of West Indies at Mona, Jamaica. PAHO published “Cancer Registry Establishment and Maintenance in Caribbean Countries”, which was disseminated to stakeholders throughout the Caribbean
- **2004:** Feasibility and assessment study for cancer registries was performed for countries part of the Organization of Eastern Caribbean States to determine infrastructure needs
  - Antigua and Barbuda, St. Kitts and Nevis, Dominica, St. Vincent and the Grenadines, St. Lucia, Grenada
- **2010:** Training in CANREG 5 (collaboration between Caribbean Public Health Agency and IARC)
  - Six participating countries: Barbados, Bahamas, Cayman Islands, Jamaica, Guyana, Trinidad and Tobago
- **2012:** IARC survey to identify challenges (followed by a second survey by IARC and CARPHA in 2014)

# 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 registries**
  - 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)**

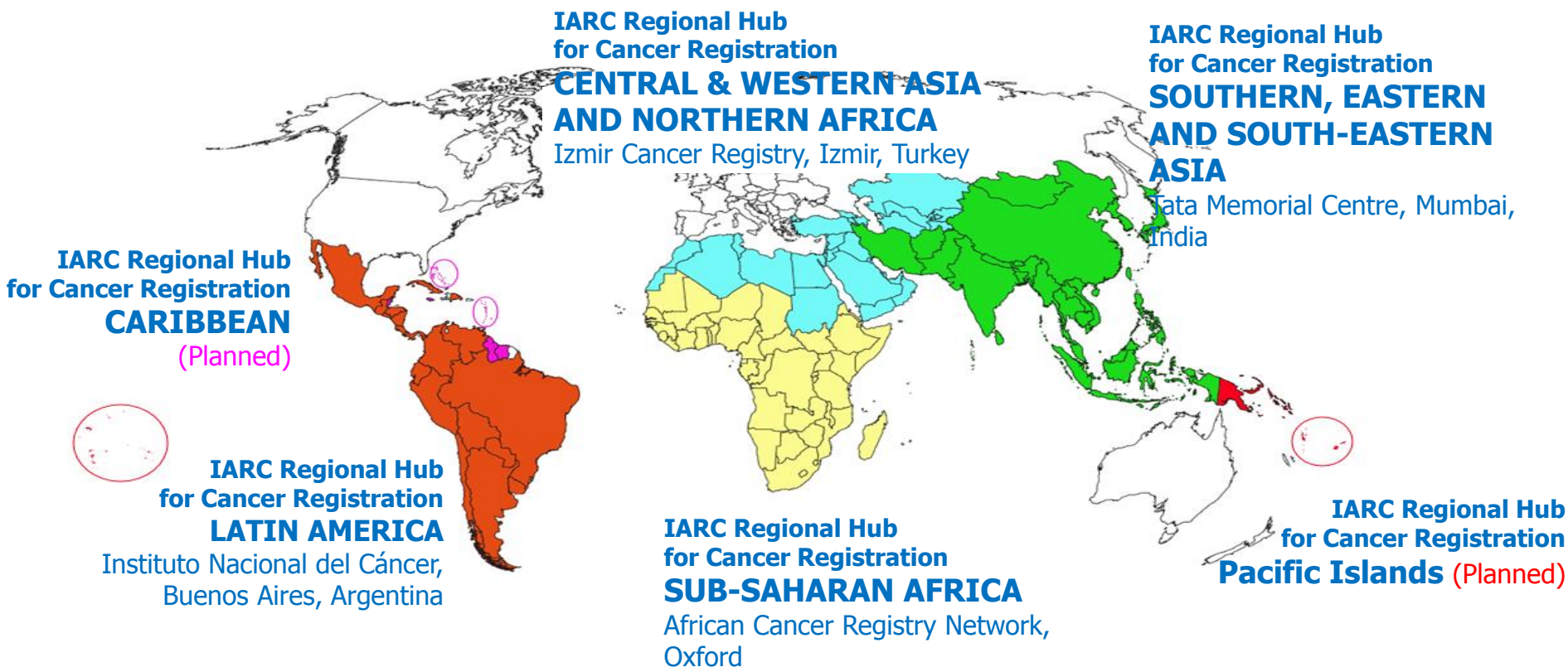
# The Global Initiative for Cancer Registry Development in Low/Middle Income Countries

- 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





# Six IARC Regional Hubs for Cancer Registration in LMIC



# Cancer Registry Webinar

Introduction of GICR to the region

Audience: MOH representative, policy-makers, NGOs, Epidemiologists, Cancer researchers (academia and private)

- History of Cancer Registration in the Caribbean
  - **Dr. Patsy Prussia, Barbados National Registry, Barbados**
- Strengthening the Caribbean's Surveillance for Regional and Global Monitoring of Cancer and Other Chronic Diseases
  - **Dr. Glennis Andall-Brereton, CARPHA, Trinidad and Tobago**
- The Global Initiative for Cancer Registry Development (GICR)
  - **Dr. David Forman, IARC, France**

# Cancer Surveillance for the Caribbean

## Partners:

- National Cancer Institute
- The Caribbean Public Health Agency
- Pan American Health Organization
- US Northern Command
- Centers for Disease Control and Prevention
- International Agency for Research on Cancer
- The African Caribbean Cancer Consortium

**Overall objective:** to stimulate strengthening of registration for cancer and to encourage strategic use of information for national cancer control plans and programs

# Goals for Cancer Surveillance meeting

- Share information on the various global, regional and sub-regional initiatives on cancer registration
- Establish an up-to-date status of cancer surveillance in the Caribbean
- Identify and address specific capacity building needs relevant to the Caribbean
- Encourage collaborative research between registries and cancer researchers
- Provide support for country efforts to improve cancer registration and use of data for planning and evaluation of cancer plans and programs and research

# Strategic planning

- What do you need to establish or improve a cancer registry in your institution/country?
- What are the specific training AND retention needs for cancer registration in your institution/country? How can these training needs best be met?
- In your institution/country how can a cancer registry be funded and sustained?
- How can external organizations such as CARPHA, CDC, IARC, NCI and PAHO help to strengthen cancer and non-communicable diseases registration in the Caribbean?
- What are your suggestions to organize cancer registration in the Caribbean? How would smaller islands/populations be best served? How could synergies be developed with registration of other non-communicable diseases?

# Current state of Cancer registration in the Caribbean

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

# Meeting Recommendations

## Needs Assessment:

- Determine the current status, available infrastructure and resources
- Assess data quality

## Capacity building for services and policies that will support high-quality cancer registries:

- Improving healthcare and pathology services, data security and confidentiality
- Make cancer a reportable disease and enforce policy

## Training:

- Technical aspects of registration, analysis of data, epidemiology, grant writing, etc.

## Expansion of Economic planning tool for the Caribbean:

- CDC's planning tool to determine cost of sustaining a registry

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# GICR Caribbean Registry Hub

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

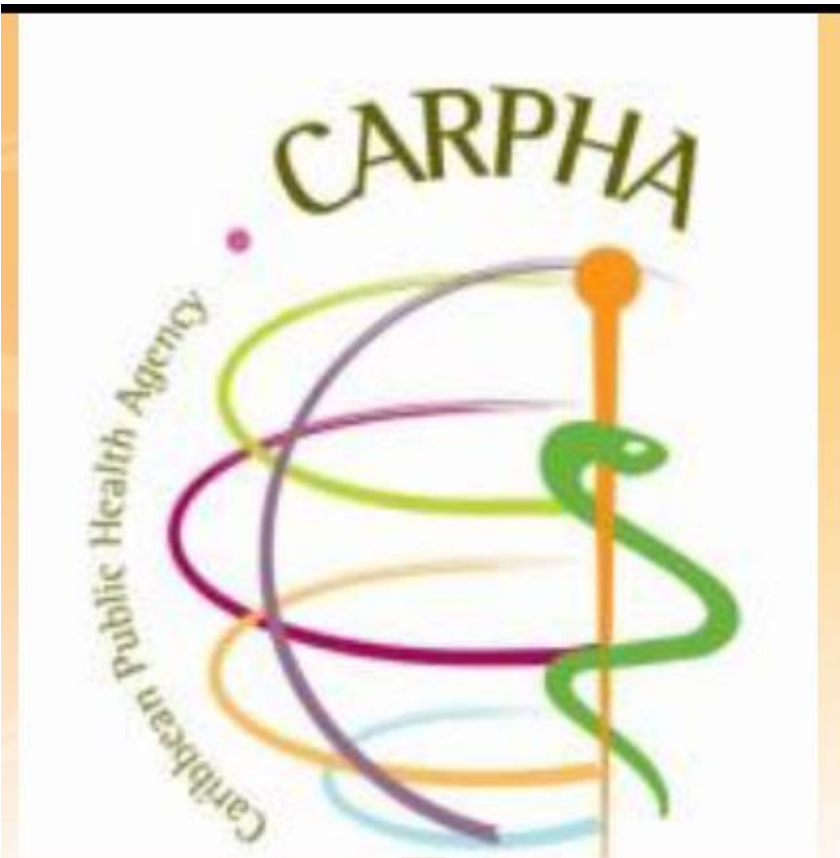
Collaborate with NAACCR

Hub will be located at CARPHA in Trinidad and Tobago

- Site visit in January, 2015

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.

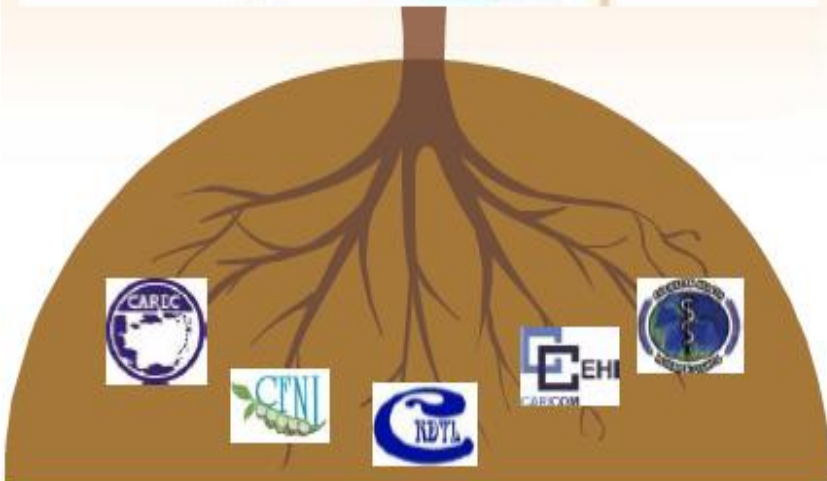


Legally established in July 2011  
and officially in 2013

Combination of five former  
Caribbean agencies

- CAREC
- CEHI
- CFNI
- CHRC
- CRDTL

Headquartered in Trinidad and  
Tobago with locations in St. Lucia  
and Jamaica



Serves 23 member Caribbean  
countries with ongoing regional  
collaborations with non-member  
states and international  
collaborations

# Hub activities

## **Provide localized training (technical and administrative)**

- Annual courses related to cancer registration
- 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

# 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

# Steering Committee

Responsible for the planning and launching of the Caribbean Hub.

Steering Committee:

- US National Cancer Institute (US NCI)
- US Centers for Disease Control and Prevention (US CDC)
- International Agency for Research in Cancer (IARC)
- Caribbean Public Health Agency (CARPHA)
- International Association of Cancer Registries (IACR)
- Co-PI (as identified by CARPHA)

# Advisory Committee

## **Provide leadership and strategic direction**

- Implementation and review of activities

## **Support the Hub in the provision of advice**

- Given regional priorities and the available resources

## **Support in planning:**

- Reviewing and following-up the current operational plans  
Identifying opportunities for the coordination of activities between organizations
- Planning the development of training courses
- Establishing working groups to assess priorities
- Initiation of and development of research activities
- Formulating proposals for fundraising.

# Advisory Committee

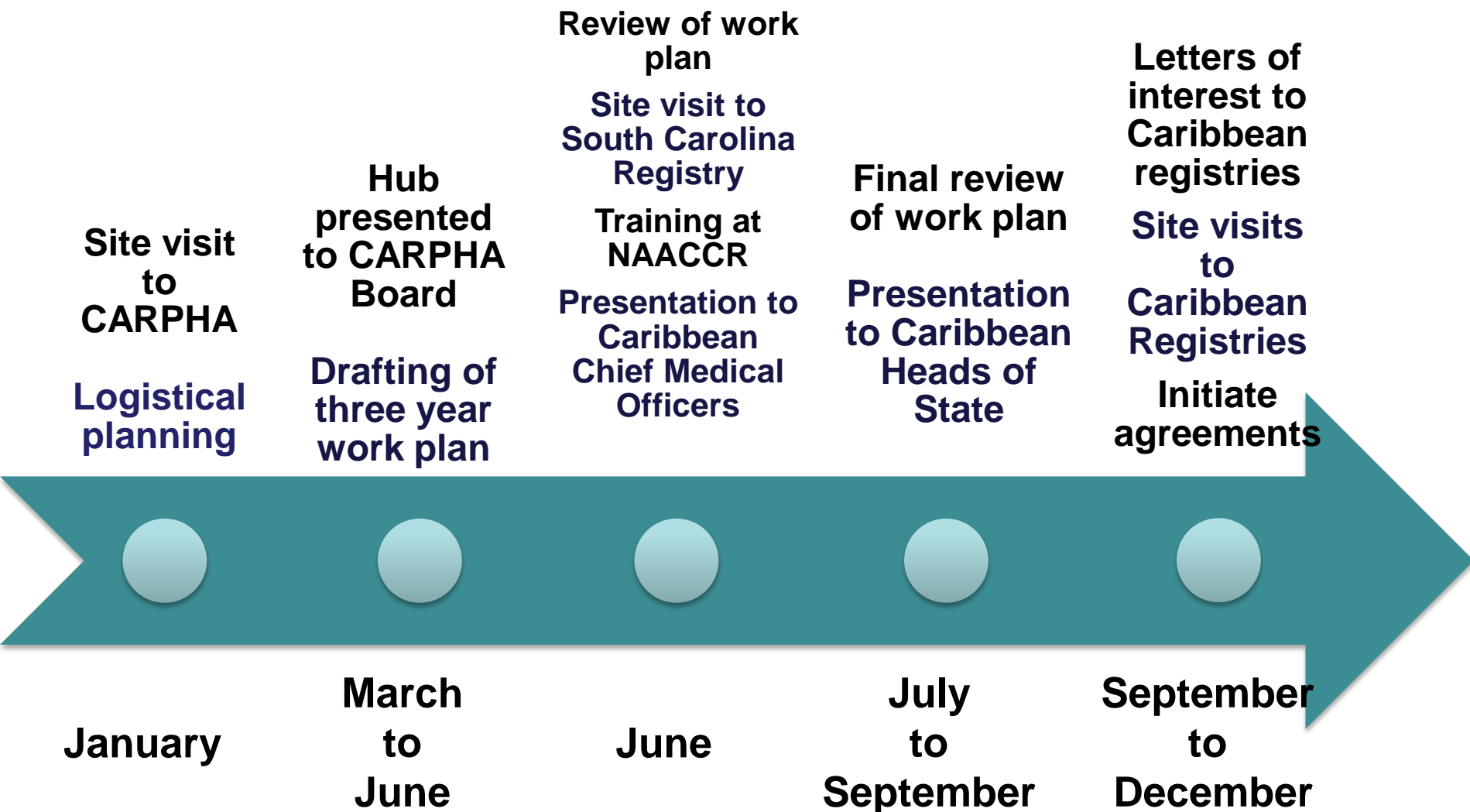
## **Support in implementation:**

- Developing and dissemination of guidelines and standards for registry operations
- Harnessing networking and advocacy activities across the Hub region
- Promoting the awareness of the Hub related activities.

## **Support in evaluation:**

- Participating in the evaluation of Hub activities according to agreed short- and long-term indicators.

# Timeline of Caribbean Registry Hub Activities, 2015





# Relevance to United States

3.5 million Caribbean immigrants in the US in 2009

6.0 million people in the US self-identified as being from the Caribbean diaspora

How does this affect cancer burden in the US?

- Baseline information from country of origin

Cancer patterns among Caribbean immigrants

- Should be studied separately (Afro-Caribbeans vs. African-Americans)
- Risk factors
- Admixture
- Cancer etiology
- Cancer trends

Thank you!