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# Caribbean Hub for the Global Initiative for Cancer Registries

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June 16<sup>th</sup>, 2016***

# 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



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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**



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# Cancer Registration in the Caribbean

Country	Year Started	Coverage
Puerto Rico	1950	National
Jamaica	1959	Urban
Cuba	1964	National
Netherland Antilles	1977	National
Bermuda	1979	National
Martinique	1983	National
Trinidad and Tobago	1994	National
Guyana	2000	National
French Guiana	2005	National
Guadeloupe	2008	National
Barbados	2010	National
Cayman Islands	2010	National

# Situation Analysis: Cancer Registration 2014

## □ IARC/NCI/CARPHA

- Objectives
  - To a develop 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

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

# Global NCD Reporting Requirements :

## UNITE IN THE FIGHT AGAINST NCDs

2011 UN High-level meeting on NCDs

General Assembly • United Nations • New York

19–20 September 2011



World Health  
Organization

## 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

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

# The Global Initiative for Cancer Registry (GICR) 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



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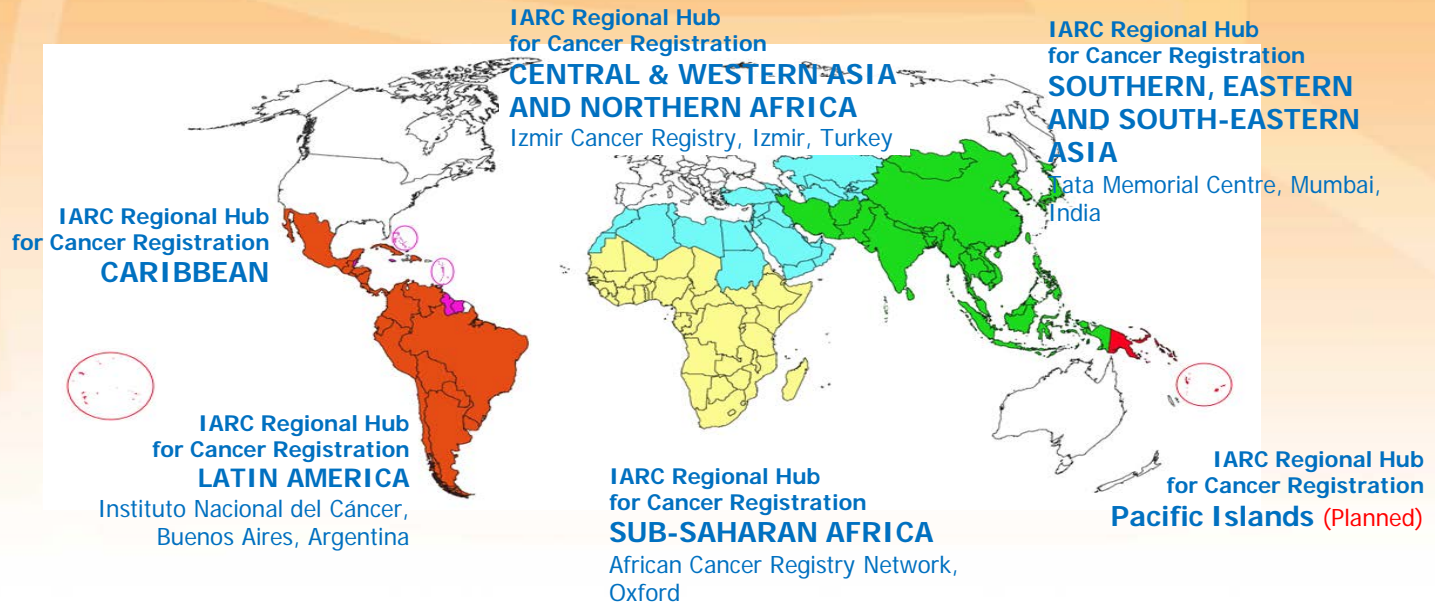
Source, IARC

# 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



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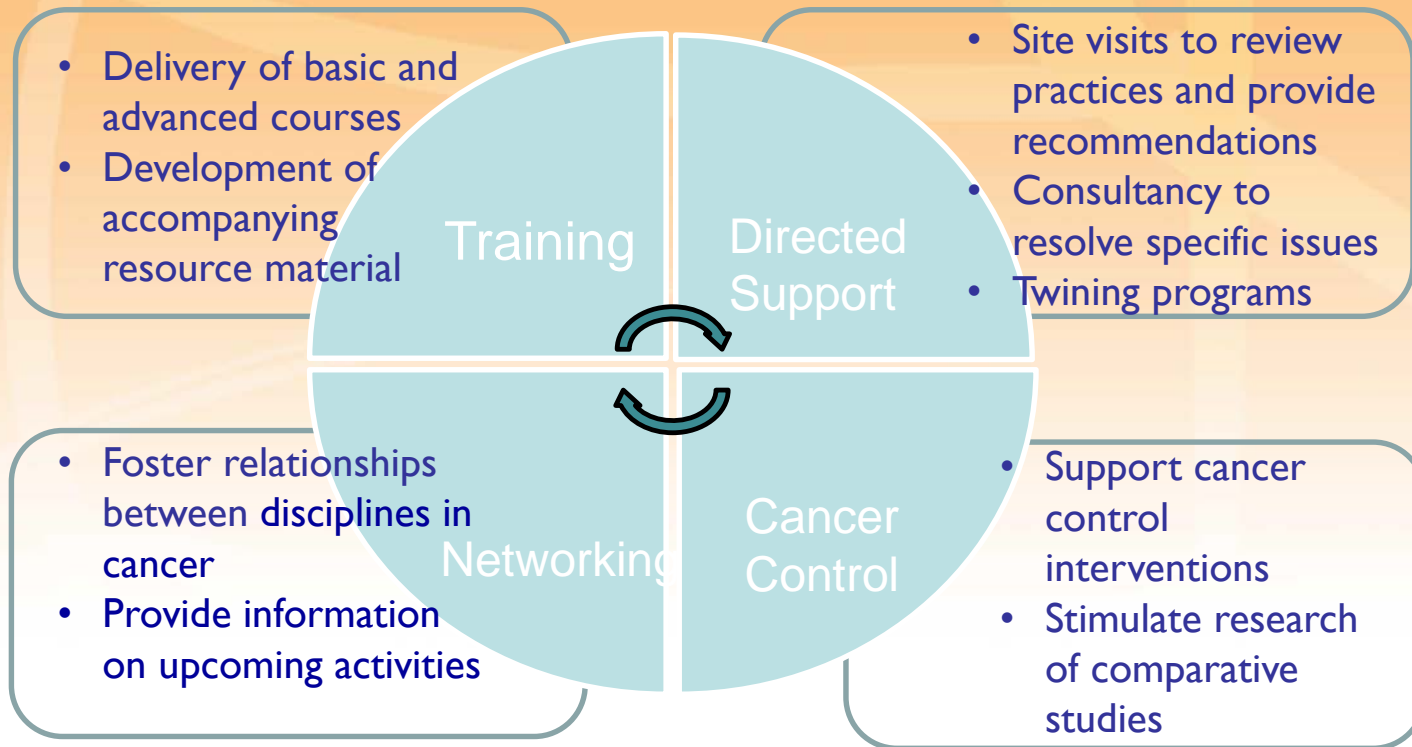
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Source, IARC

# IARC Regional Hubs: Core Areas of Focus



# GICR Caribbean Registry Hub

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.



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**National Cancer Institute**



# Caribbean Hub activities

## Provide localized training (technical and administrative)

- Annual courses related to cancer registration
  - 1st Course – June 20-21<sup>st</sup> (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



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**National Cancer Institute**

# 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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