



# **Improving Data Collection and Use of Data for the Implementation of National Cancer Control Plans**

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# Presentation Outline

- ① Cancer registries and cancer control
- ② Implementation: country examples
  - Rwanda; Mexico; and Myanmar
- ③ Data for policy action
- ④ Support: the Global Initiative for Cancer Registry Development (GICR)

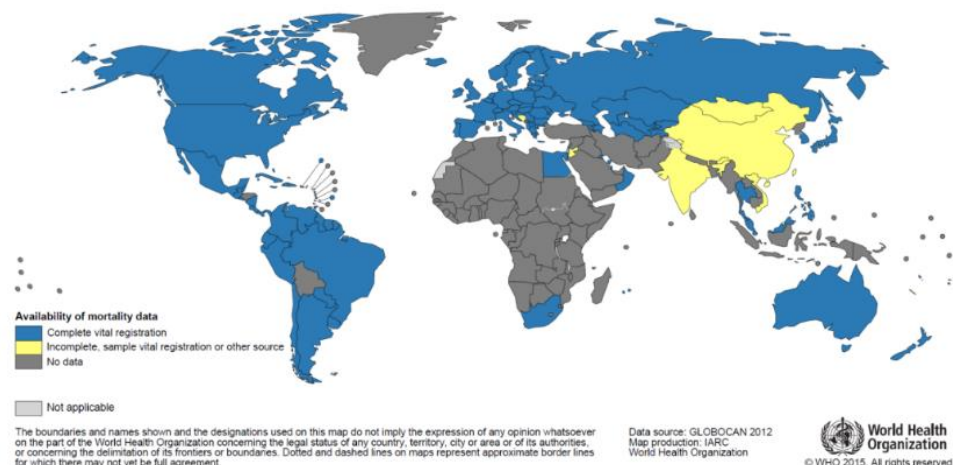
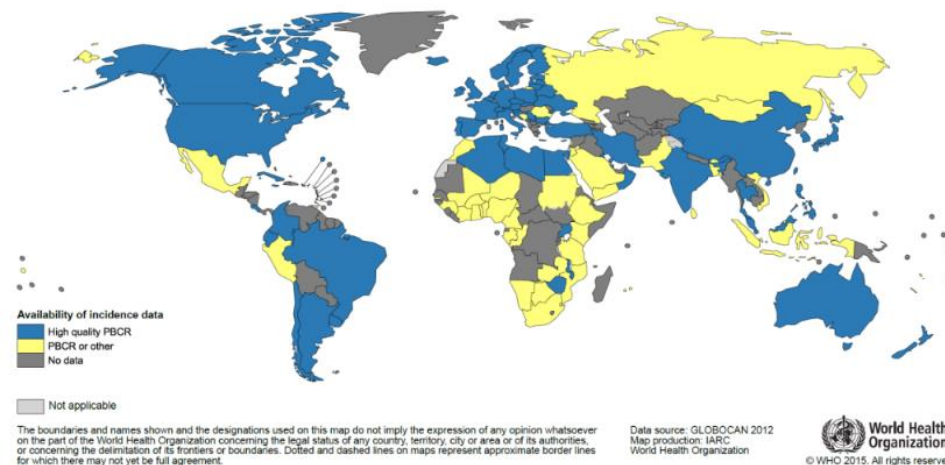
# National cancer control plans require surveillance and monitoring

- What is the cancer burden in the country?
- How is it likely to evolve? Where to invest?
- How successful are the implemented cancer control policies?

Two cancer surveillance mechanisms available (and complementary):

- For mortality: vital statistics on deaths (by cause)
- For morbidity: disease (**cancer**) registers

# Data availability: Worldwide



INCIDENCE

36%

Only 67 of 184 countries report high quality incidence data to IARC<sup>1</sup>

MORTALITY

19%

Only 34 of 178 countries report high quality mortality data to WHO<sup>2</sup>




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<sup>1</sup> Cancer Incidence in Five Continents Volume X

<sup>2</sup> WHO Mortality Database

# Types of Cancer Registries

Characteristics, purposes and uses of different types of cancer registries

Registry type	Characteristics	Purpose	Can this type of registry be used in formulating cancer plans?
 <b>Hospital-based cancer registry</b>	Collects information on all cases of cancer treated in one or more hospitals	Useful for administrative purposes and for reviewing clinical performance	<b>NO</b>
 <b>Pathology-based cancer registry</b>	Collects information from one or more laboratories on histologically diagnosed cancers	Supports the need for laboratory-based services and serves as a quick "snapshot" of the cancer profile	<b>NO</b>
 <b>Population-based cancer registry</b>	Systematically collects information on all reportable neoplasms occurring in a geographically defined population from multiple sources	The comparison and interpretation of population-based cancer incidence data to support population-based actions aimed at reducing the cancer burden in the community	<b>YES</b>

Source: Bray et al. (2014) Planning and Developing Population-Based Cancer Registration in Low- and Middle-Income Settings. IARC Technical Publication No. 43. Lyon: International Agency for Research on Cancer. Available from: <http://publications.iarc.fr>

# What is a PBCR?

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A Population-Based Cancer Registry (PBCR) is an ongoing surveillance system to collect, store, manage, analyse and disseminate information on the **occurrence of cancer in a defined population.**

Indicator obtained



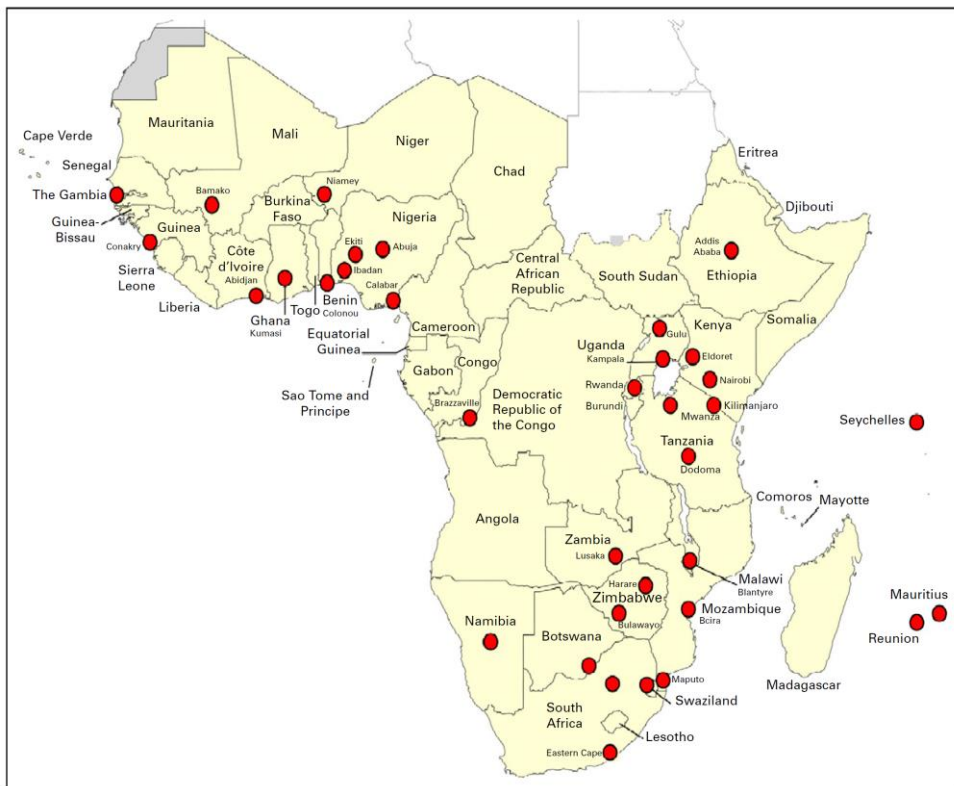
**Cancer incidence rates by type of cancer for the defined population.**

Source: Piñeros et al. A Global Cancer Surveillance Framework Within Noncommunicable Disease Surveillance: Making the Case for Population-Based Cancer Registries. Epidemiol Rev. 2017 Jan 1;39(1):161-169



# African Cancer Registry Network (AFCRN)

- GICR partners with AFCRN to provide a network Regional Hub for registration in Sub-Saharan Africa (SSA)
- AFCRN aims to improve the effectiveness of cancer surveillance in SSA, providing expert evaluation of current problems and technical support to remedy identified barriers.
- Presently 35 Member Registries in 24 countries
- *Cancer in Africa* series and recent research reports provide key data on cancer incidence and survival in the region
- Basis for national GLOBOCAN incidence and mortality estimates contained within GCO



**IARC**  
**REGIONAL HUB**  
**FOR CANCER**  
**REGISTRATION**  
SUB-SAHARAN AFRICA



# Cancer surveillance - PBCR for cancer control

## Data production

### GICR Partner Countries

- Targeted assistance in technical assistance, training and mentorship
- Based on local commitment
  - Investments in registration
  - Implementation plan

Data Collection

Data Processing

Data Analysis

Data Dissemination Communication

## Data use in cancer control

Evaluation

Implementation

Planning

Cancer Control

Data Dissemination Communication



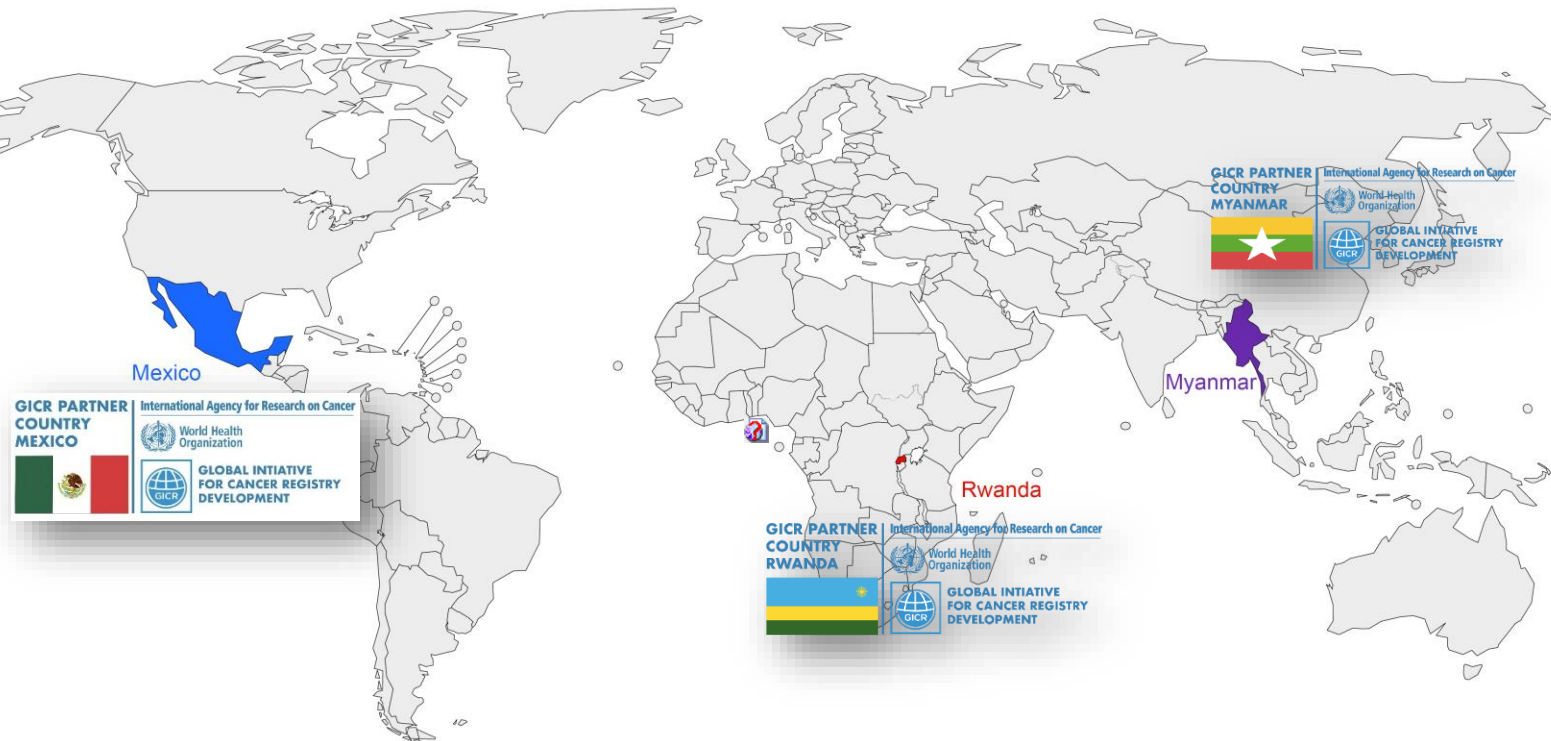
Stakeholders involved in data production & data use for  
cancer control and cancer research

Adapted from: Remington P. In: Lee et al. Principles and Practice of Public Health Surveillance; Oxford 2010.



# GICR Partner Countries – path to progress

9



The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

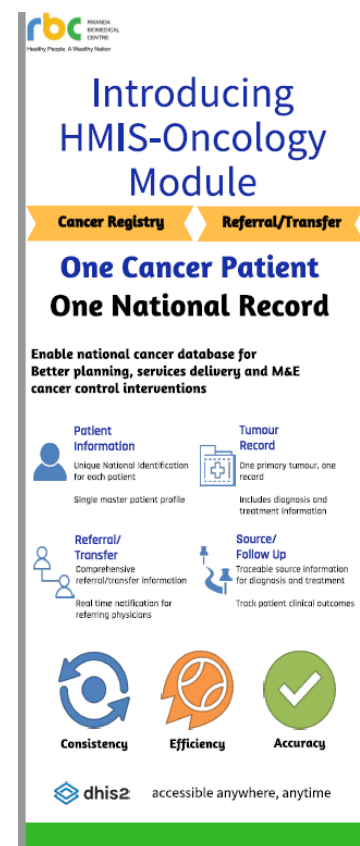
Map production: CSU  
World Health Organization



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# Rwanda National Cancer Registry

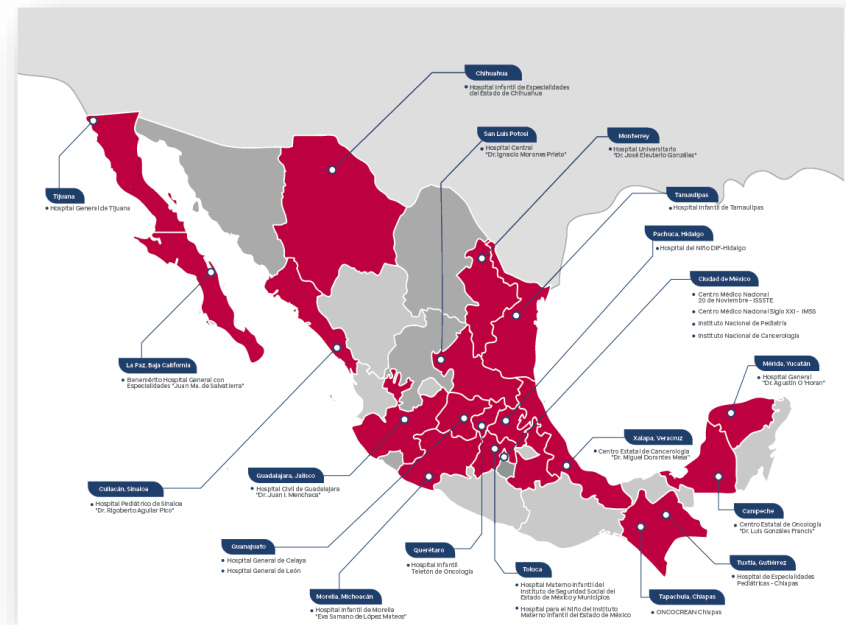
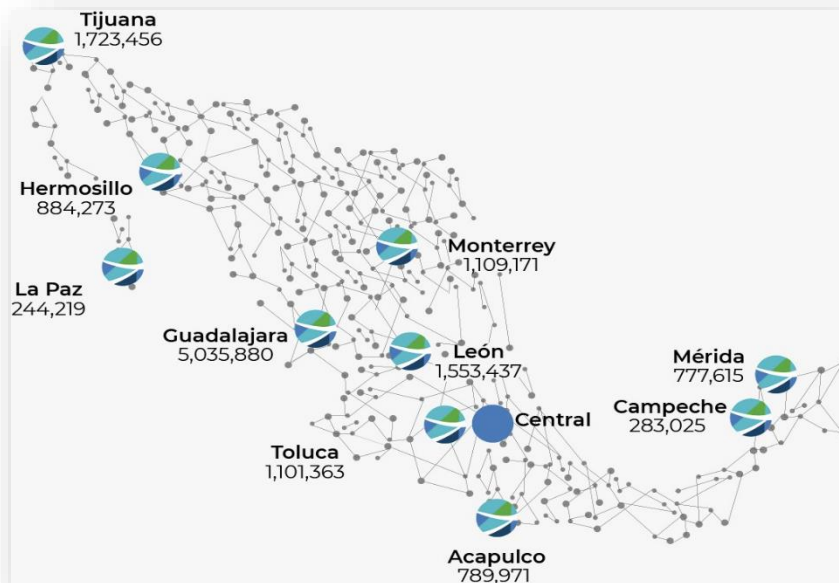
- Supporting the Rwanda National Cancer Registry in Rwanda leverage existing technology platforms.
- Develop the Interoperability between DHIS-2 and CanReg5, transfer exportable files, or direct linkages
- Applicable to countries using DHIS-2 to facilitate or initiate cancer registration at the population level.



# Building synergies in childhood cancer registration in Mexico

## St Jude's Paediatric Cancer Hospitals Network

### National Cancer Registry Network



# Building registry capacity in Myanmar- the power of partnerships

GICR Phases	Key Activities	IARC Partners*
<b>1 COUNTRY ASSESSMENT</b> <ul style="list-style-type: none"> <li>Review cancer and vital registries to determine opportunities</li> <li>Identify local leaders</li> </ul>	<b>2014</b> <ul style="list-style-type: none"> <li>Discussions with local contacts on needs – leading to a course on basic cancer registration in Yangon</li> <li>Installation and customization of IARC CanReg5 software</li> <li>Agreement with the Ministry of Health and Sports (MoH) to launch pilot cancer registry, Naypyidaw General Hospital</li> </ul>	<ul style="list-style-type: none"> <li>IARC Mumbai Hub</li> <li>National Cancer Institute (Thailand)</li> <li>Myanmar MoH</li> <li>International Association of Cancer Registries</li> </ul>
<b>2 SITE VISIT</b> <ul style="list-style-type: none"> <li>Establish the basis for an implementation plan</li> <li>Meet with stakeholders to provide recommendations</li> </ul>	<b>2015</b> <ul style="list-style-type: none"> <li>ImpACT Mission to review cancer control services in Mandalay, Naypyidaw and Yangon</li> <li>Debriefing with senior MoH staff to refine recommendations</li> </ul>	<ul style="list-style-type: none"> <li>International Atomic Energy Agency</li> <li>World Health Organization</li> </ul>
<b>3 DIRECTED SUPPORT</b> <ul style="list-style-type: none"> <li>Establish the IARC Hub as the first point of contact</li> <li>Coordinate opportunities with other partners for efficiency</li> <li>Promote accountability via a signed agreement and the use of a monitoring framework</li> </ul>	<b>2016</b> <ul style="list-style-type: none"> <li>Engagement with surveillance leaders to establish a plan for PBCR**, Myanmar Cancer Control Leadership Forum</li> <li>Elaboration of cancer registry plan, including costing and milestones at the National Cancer Control Programme Meeting</li> <li>Naypyidaw PBCR staff selected as IARC '50 for 50' Programme</li> </ul> <b>2017</b> <ul style="list-style-type: none"> <li>IARC – MoH Collaborative Research Agreement finalized to become a <b>GICR Partner Country</b></li> <li>Delivery of a national training course</li> <li>Revisions to CanReg5 to include new fields and local language</li> <li>Naypyidaw PBCR staff training at IARC Summer School</li> </ul>	<ul style="list-style-type: none"> <li>National Cancer Institute (US)</li> <li>National Cancer Centre (Japan) / IARC GICR Collaborating Centre</li> </ul>
<b>4 GENERATE EVIDENCE</b> <ul style="list-style-type: none"> <li>Implement quality improvement methods</li> <li>Publish data from the cancer registry</li> <li>Communicate results for cancer control action</li> </ul>	<b>2018 – 2020 (PLANNED)</b> <ul style="list-style-type: none"> <li>Mentorship exchange with IARC - GICR Collaborating Centres</li> <li>Initial data quality review of Naypyidaw PBCR</li> <li>Networked version of CanReg5 system to other centres – Mandalay, Yangon and Taunghyi</li> <li>Assessment of feasibility for the implementation of PBCRs in other regions of the country</li> </ul>	<ul style="list-style-type: none"> <li>National Cancer Institute (Thailand) / IARC GICR Collaborating Centre</li> <li>International Union for Cancer Control</li> <li>Bloomberg Philanthropies</li> <li>Vital Strategies</li> </ul>

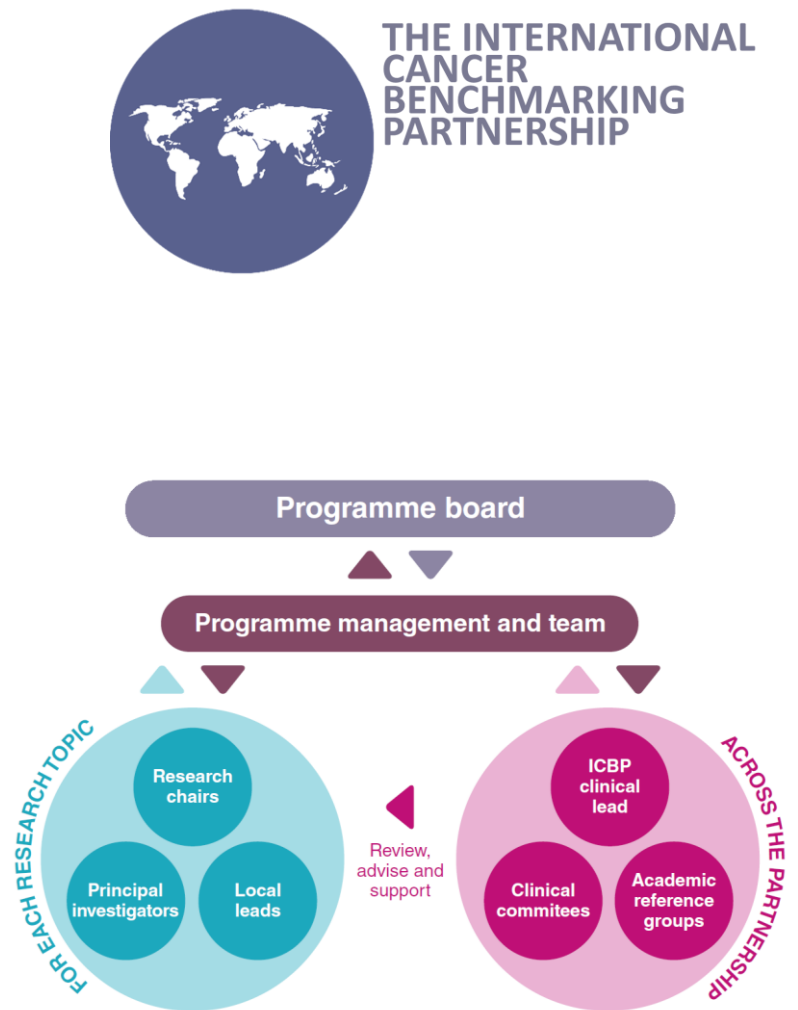
\* Listed in chronological order by involvement; \*\* Population-Based Cancer Registry



# The ICBP Partnership

- International cancer survival comparisons measuring differences and understanding factors that drive international variations in cancer survival.
- Multidisciplinary partnership of academics, clinicians, policymakers, cancer registry teams and data experts.
- Aimed at delivering high quality findings with rapid translation into practice.
- Funded by cancer charities, departments of health, cancer registries, universities in each jurisdiction. Programme Management provided by Cancer Research UK.

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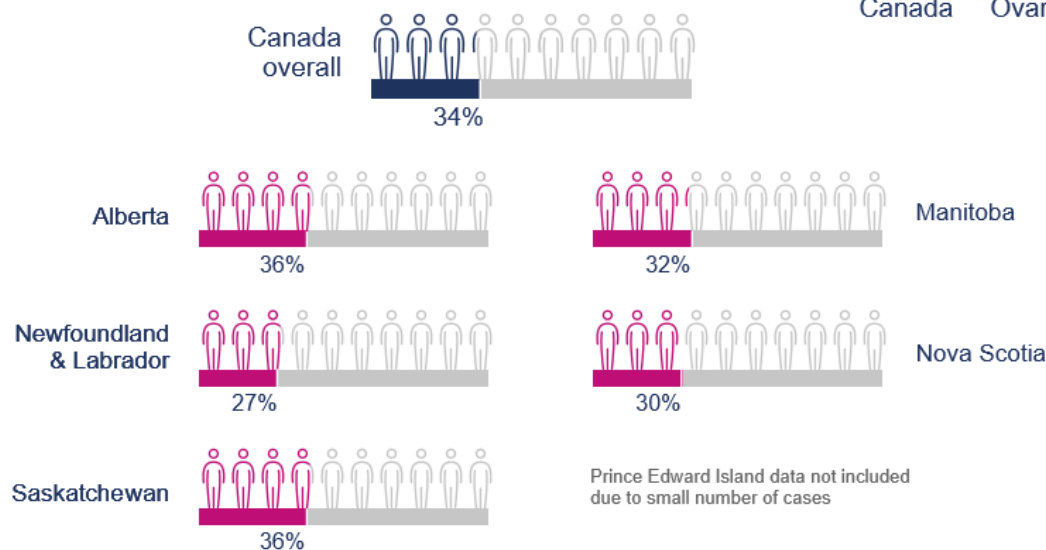


# Translation of the research results – clinical guidelines

- Clinical practice through clinical societies

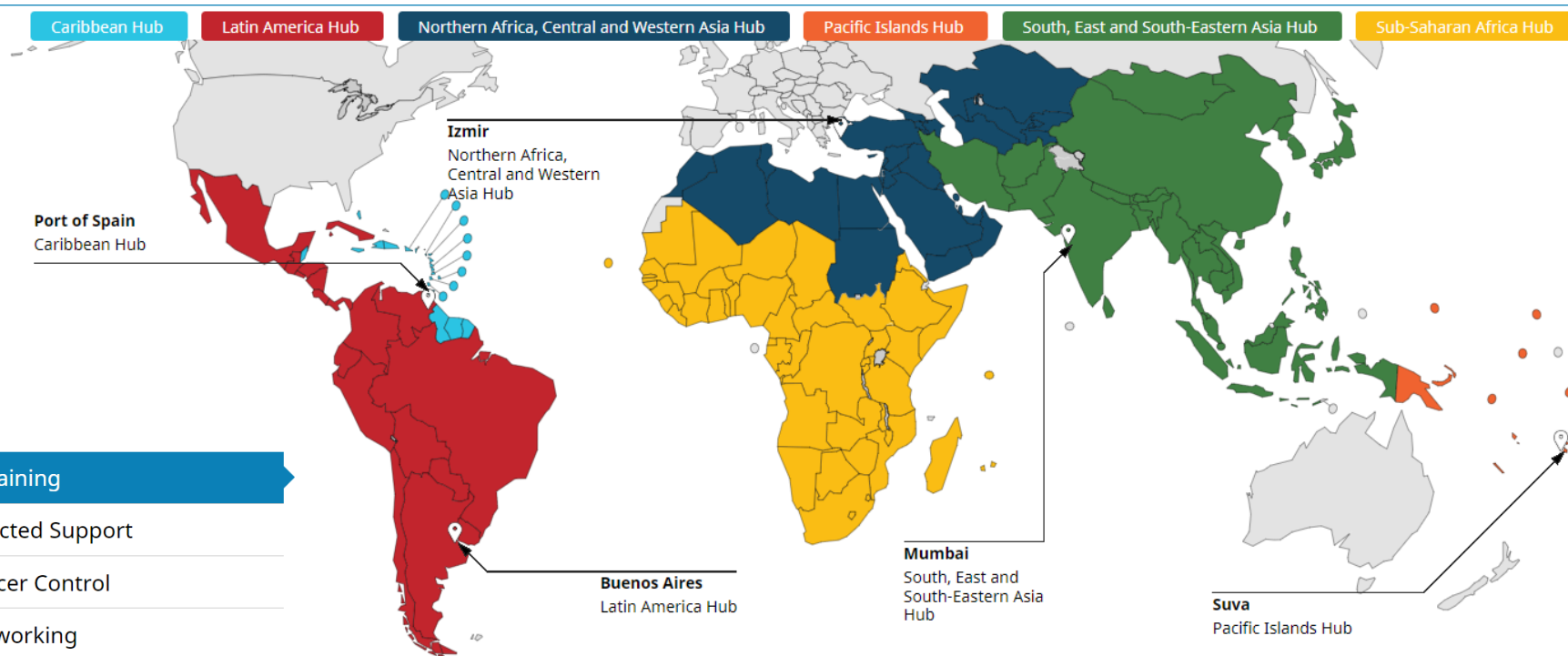
ICBP SurvMark-2:

3-year ovarian cancer survival for 65-74 year-olds with 'distant' stage disease (2010-2014)



# Support: The GICR

## Global, Regional and Local approach



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<http://gicr.iarc.fr>



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- ‘*train the trainer*’ model to form subject specific networks to deliver regional courses and provide support to registries
- Course material will be linked to joint IARC and IACR publications
- Designated leads will facilitate each group of trainers to track progress and ensure coordination



# Thank you!

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