



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

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International Agency for Research on Cancer



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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)

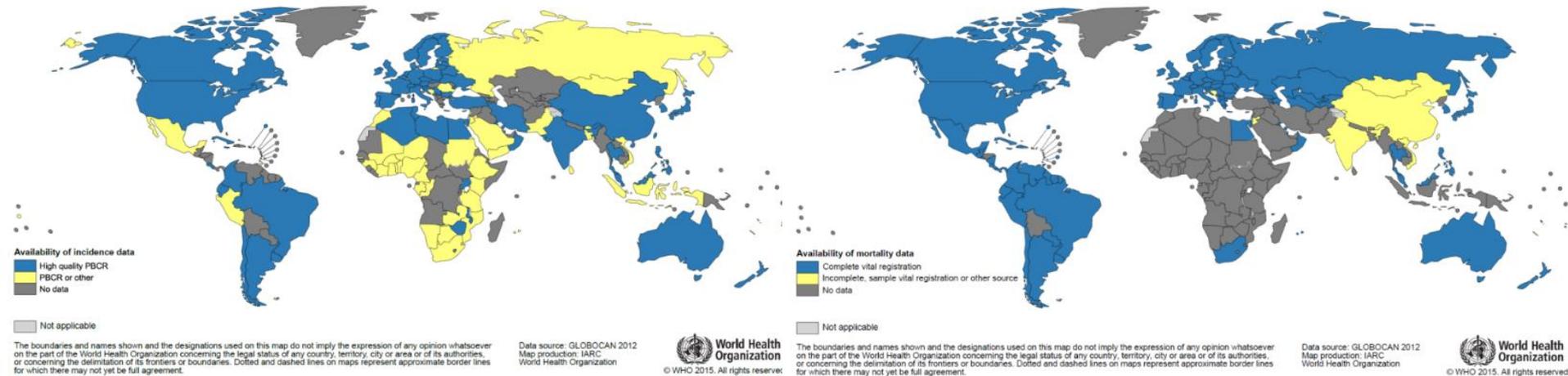
National cancer control plans require surveillance and monitoring

- 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 IARC¹

MORTALITY

19%

Only 34 of 178 countries report high quality mortality data to WHO²

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¹ Cancer Incidence in Five Continents Volume X
² 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?
 Hospital-based cancer registry	Collects information on all cases of cancer treated in one or more hospitals	Useful for administrative purposes and for reviewing clinical performance	NO
 Pathology-based cancer registry	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	NO
 Population-based cancer registry	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	YES

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?

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



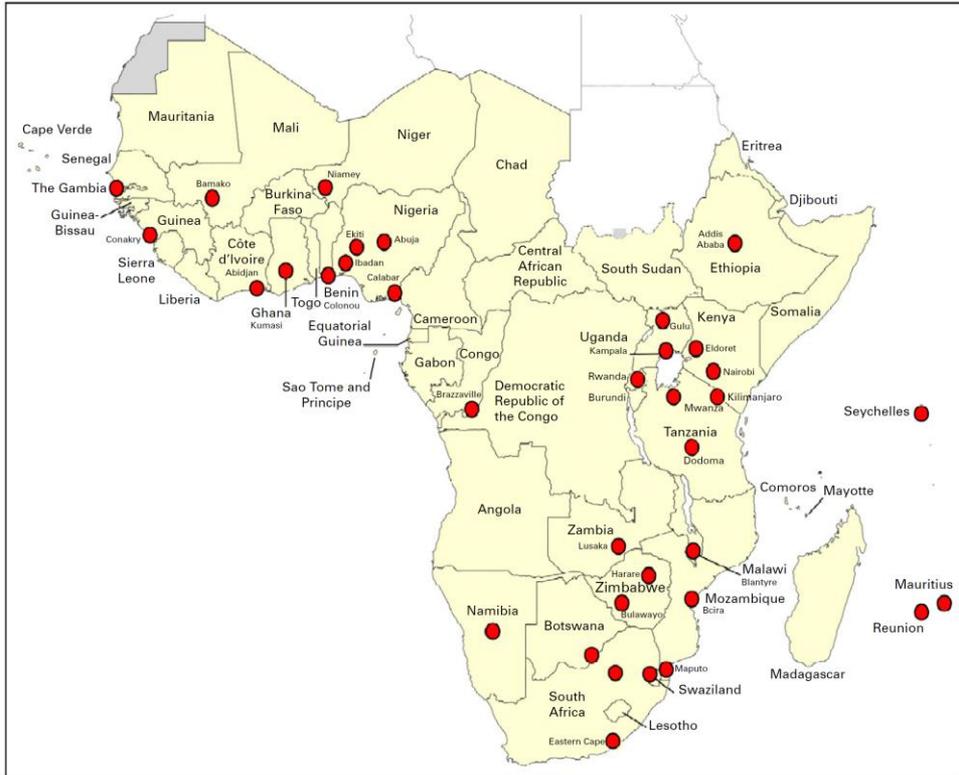
Cancer incidence rates by type of cancer for the defined population.

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

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GLOBAL INITIATIVE
FOR CANCER REGISTRY
DEVELOPMENT



GLOBAL CANCER
OBSERVATORY

Cancer surveillance - PBCR for cancer control

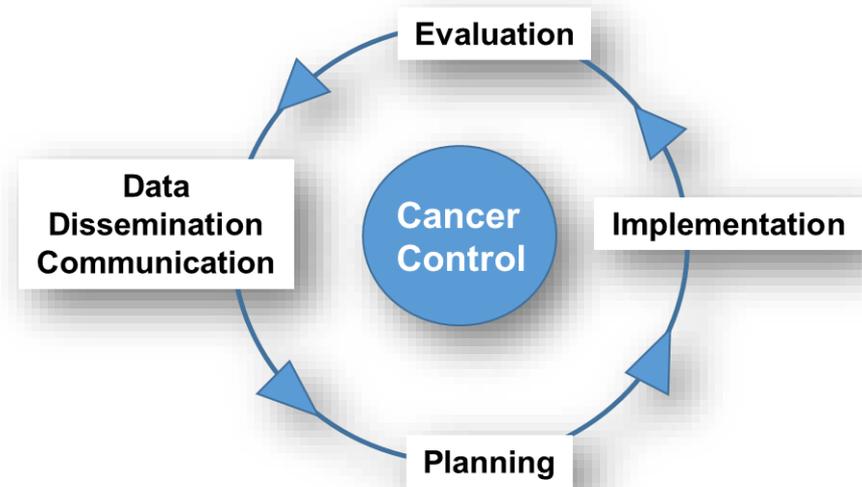
Data production

GICR Partner Countries

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

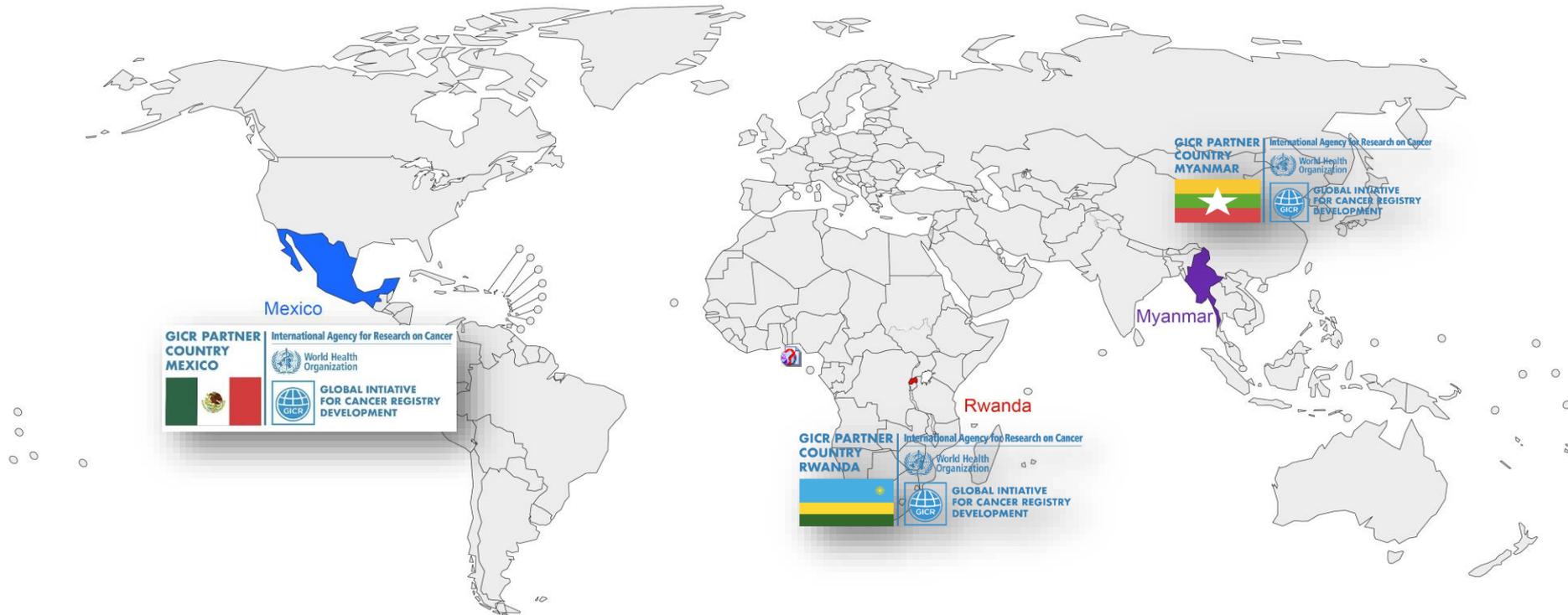


Data use in cancer control



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

GICR Partner Countries – path to progress



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.



Introducing HMIS-Oncology Module

Cancer Registry **Referral/Transfer**

**One Cancer Patient
One National Record**

Enable national cancer database for
**Better planning, services delivery and M&E
cancer control interventions**

 Patient Information Unique National Identification for each patient Single master patient profile	 Tumour Record One primary tumour, one record Includes diagnosis and treatment information
 Referral/Transfer Comprehensive referral/transfer information Real time notification for referring physicians	 Source/Follow Up Traceable source information for diagnosis and treatment Track patient clinical outcomes

Consistency **Efficiency** **Accuracy**

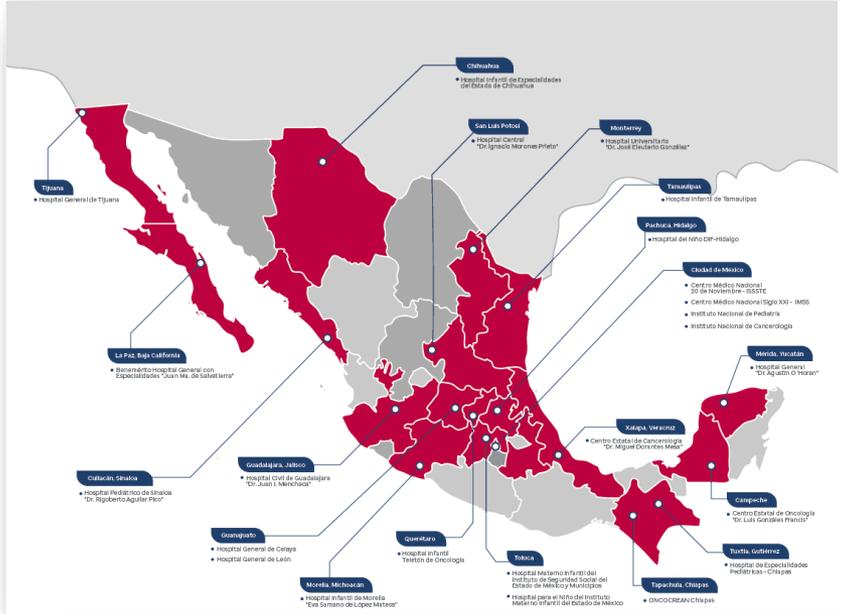
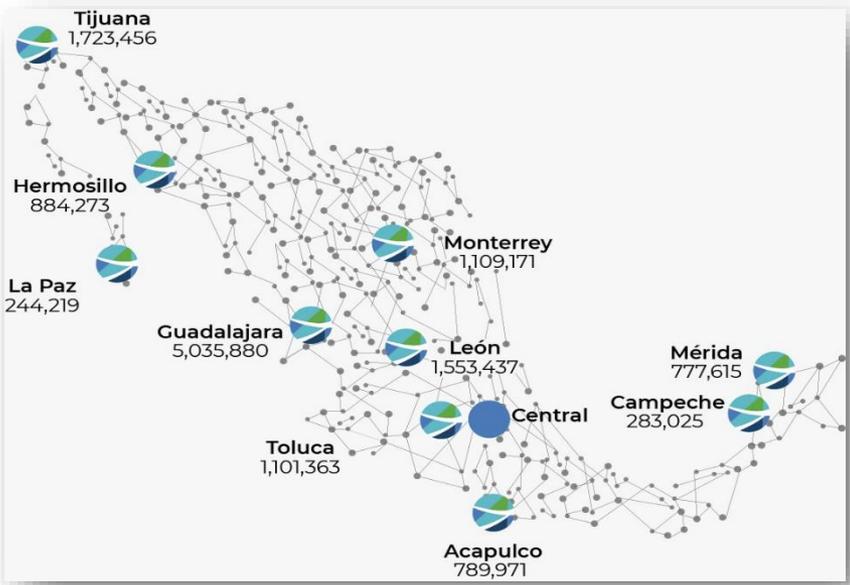
dhis2 accessible anywhere, anytime

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

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

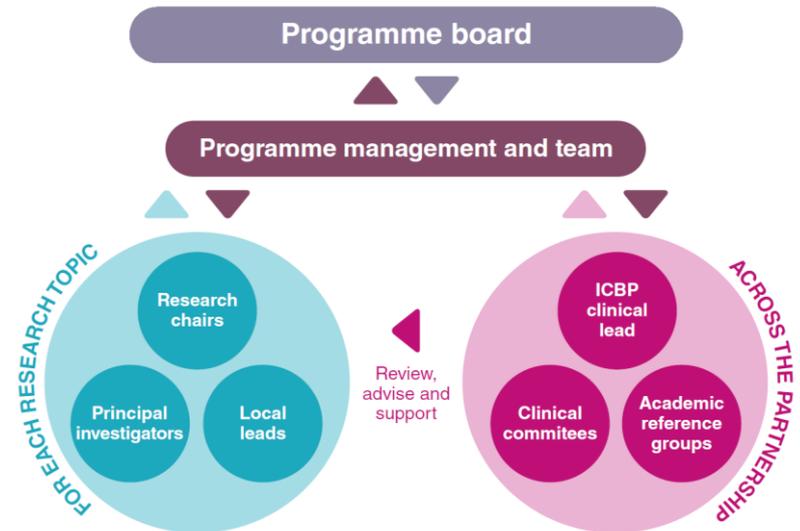
The ICBP Partnership

- 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.

[International Agency for Research on Cancer](http://www.iaircancer.org)



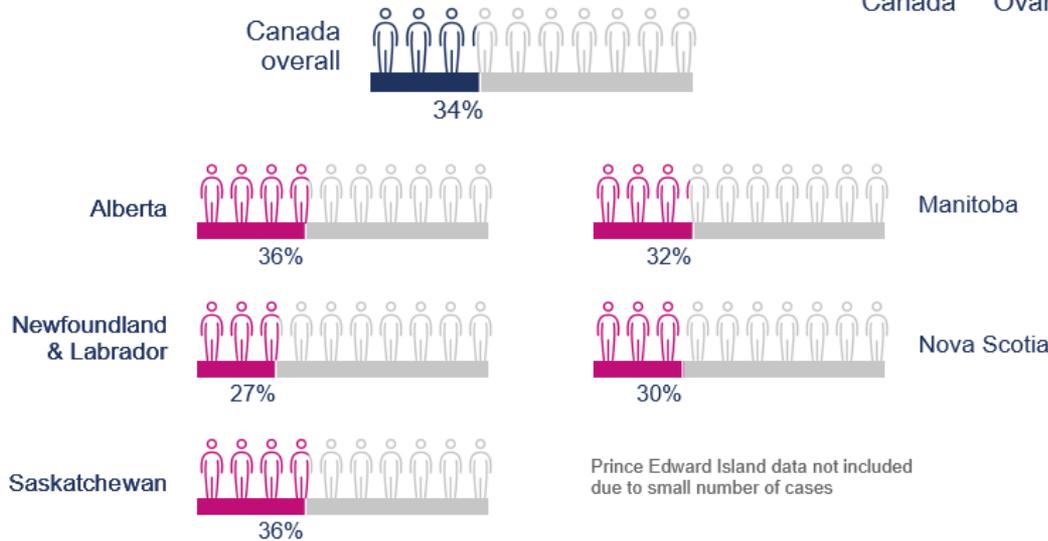
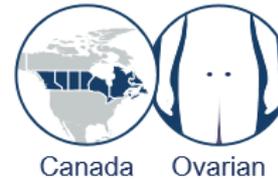
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CANCER
BENCHMARKING
PARTNERSHIP



Translation of the research results – clinical guidelines

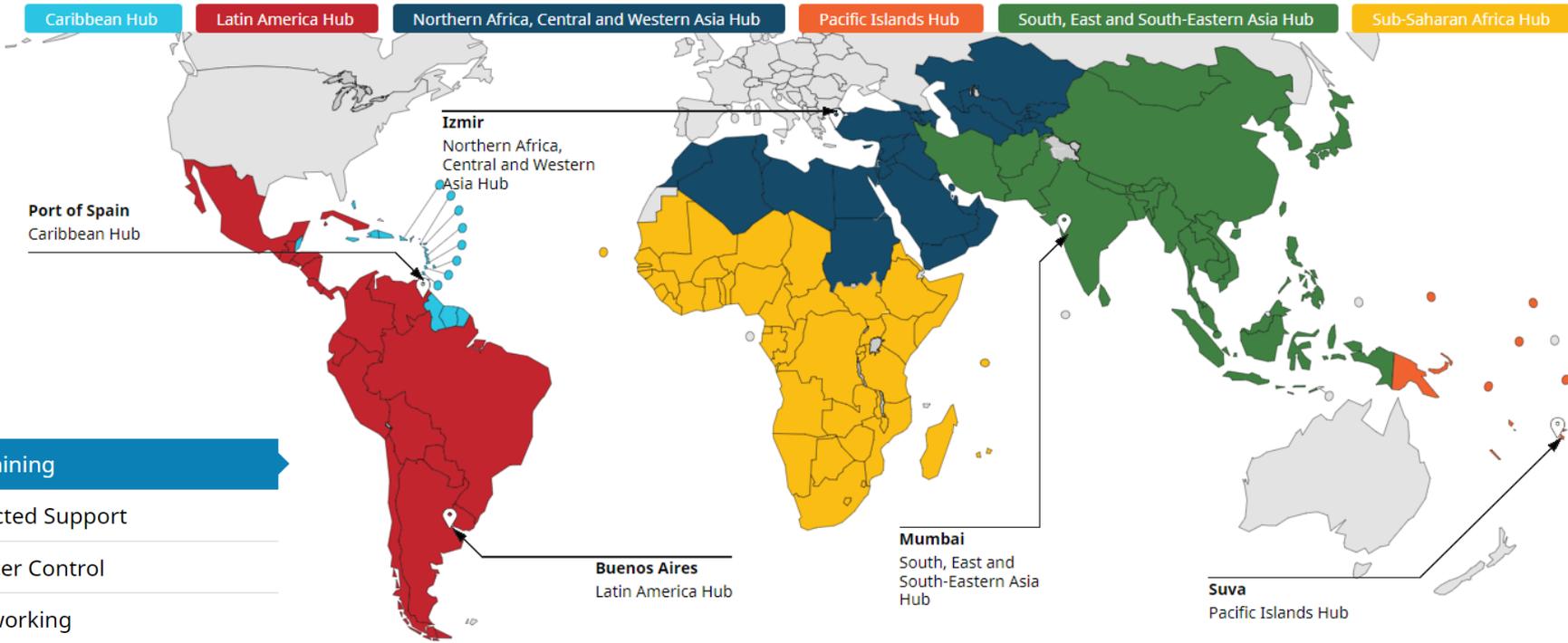
- Clinical practice through clinical societies

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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