National Cancer Institute

CENTER FOR GLOBAL HEALTH

Master Course: Cancer Control Planning and Implementation

Webinar #3

Strengthening Cancer Registries and Use of Data through National Cancer Control Efforts

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National Institutes of Health

Outline

❶Rationale for registries
  - Using Data in Cancer Control Planning

❷Types and planning

❸Key Challenges

➊ Rationale for registries

- Projected growth in new cases: 14m (2012) to over 21m (2030)
- 75% of future burden will occur in under resourced regions

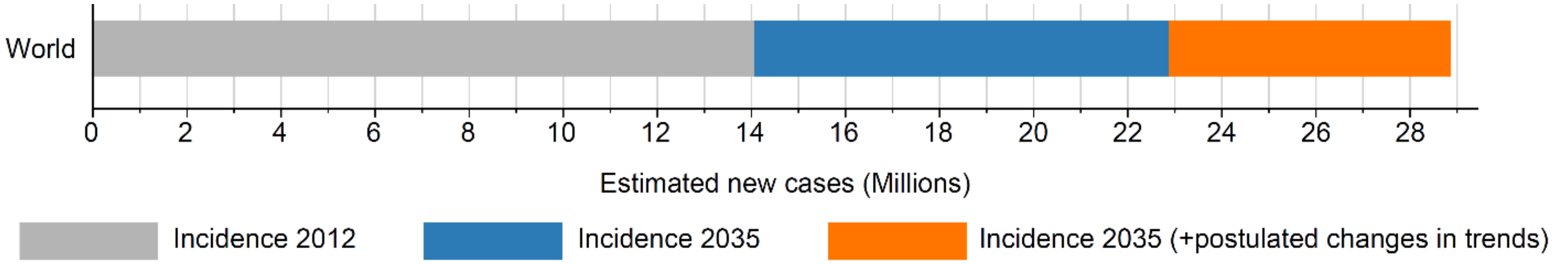
THE BURDEN

> Cancer, already the leading cause of death in many high-income countries, is set to become a major cause of morbidity and mortality in the next few decades in every region of the world, irrespective of level of resource.
>
> — *Bray F et al.,* Lancet Oncology, *2012*

Growth of New Cancer Cases

The annual number of new cancer cases in the world is predicted to increase from over 14 million in 2012 to almost 22 million in 2030 due to population growth and aging alone. The biggest increases of 70% will be seen in Africa, Asia and Latin America, which include many countries that lack adequate resources to deal with the rising number of cancer patients.

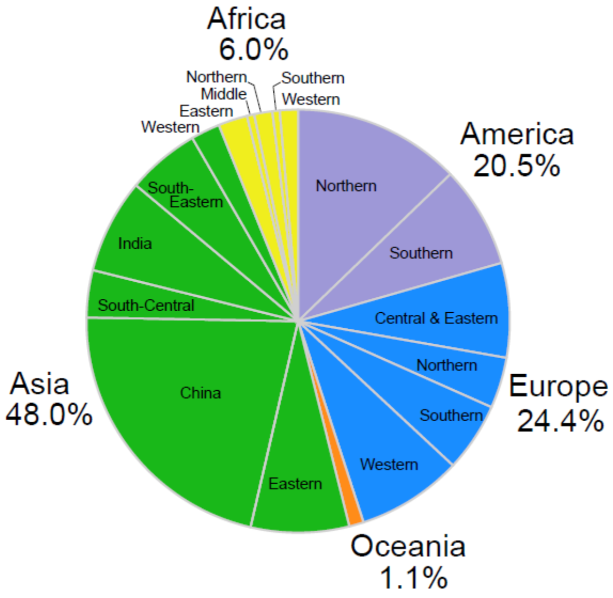
Source: World Cancer Atlas



Work in progress. Source: GLOBOCAN/CI5

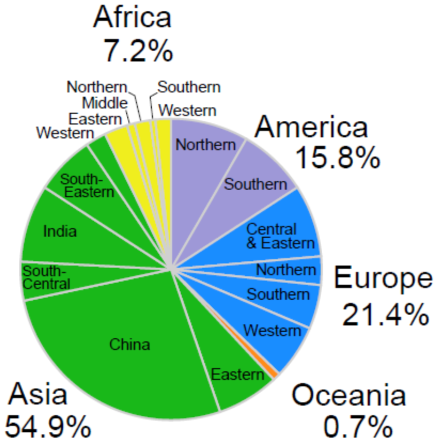
Global cancer burden 2012

Incidence



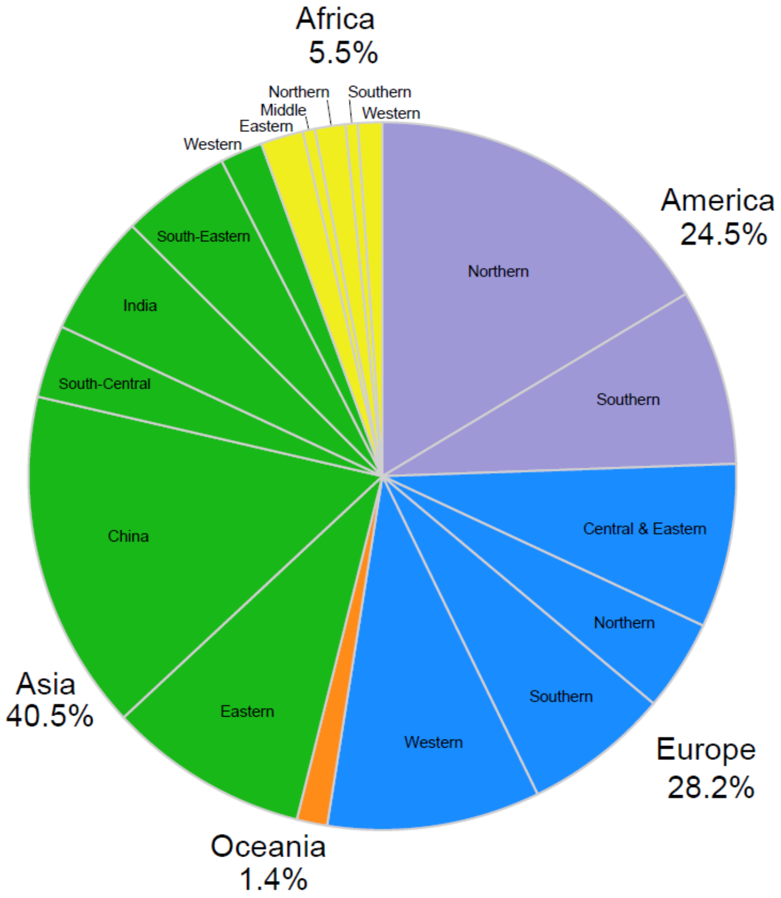
14 100 000
new cases

Mortality



8 200 000
deaths

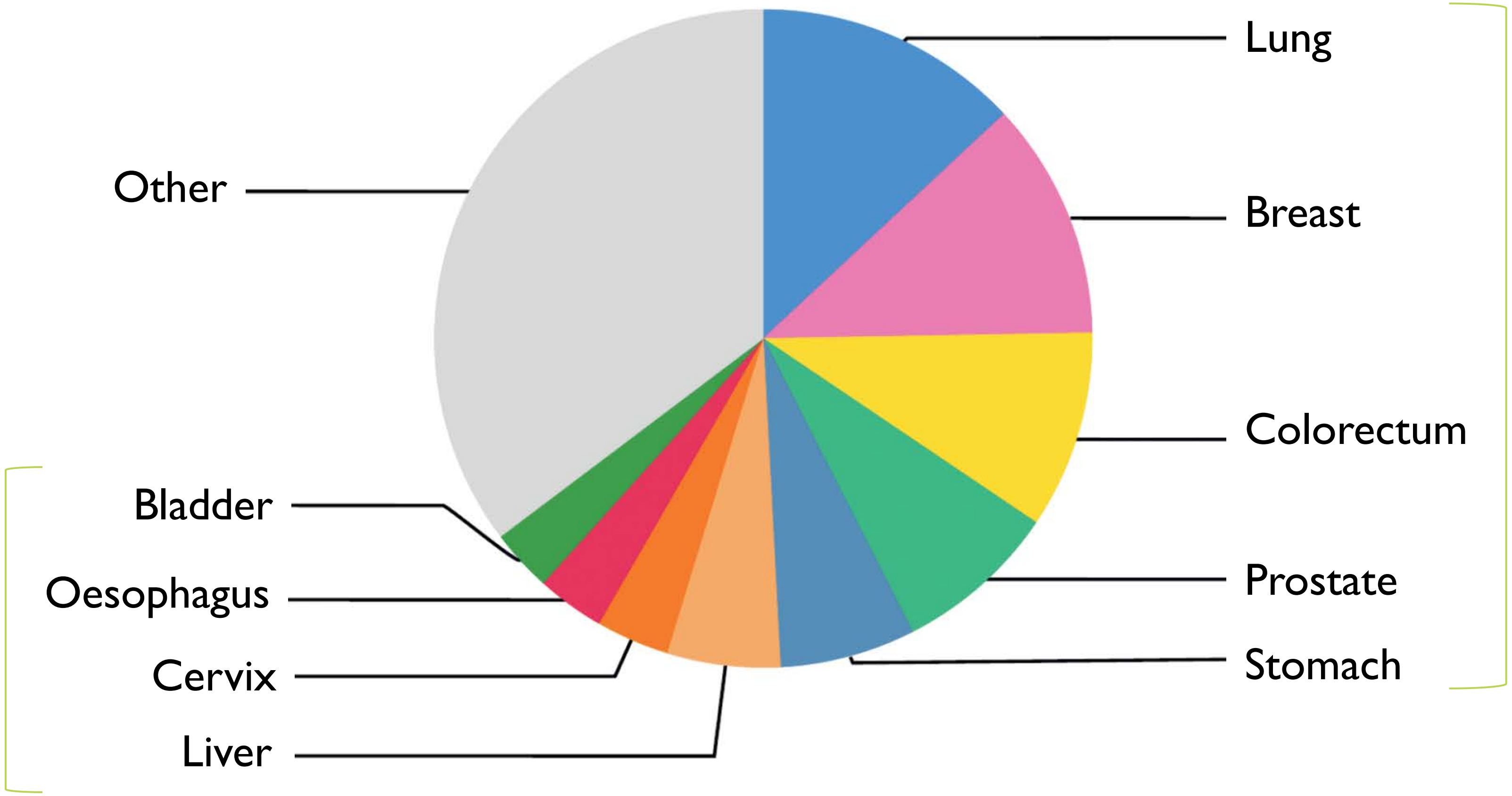
Prevalence (5 years)



32 500 000
persons

Source: GLOBOCAN 2012 http://globocan.iarc.fr

Global cancer incidence 2012



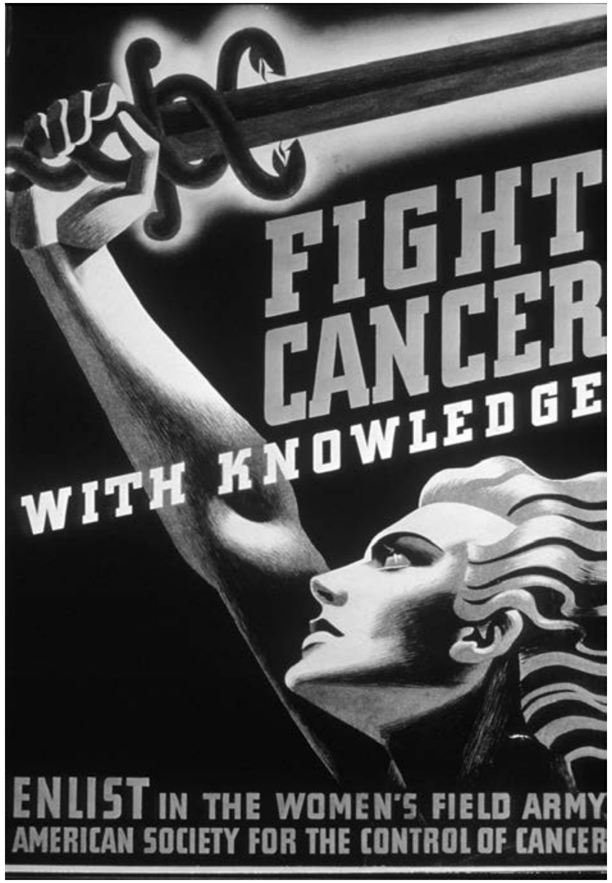
<50%

>15%

Using Data in Cancer Control Planning

Uses for data in cancer control planning

- Identify needs across the spectrum of cancer control activities
(i.e., from prevention ➔ survivorship)
- Assess and monitor efforts
- Understand the potential impact of interventions/
make evidence based policy
- Motivate key partners to take action
- Generate support for your efforts

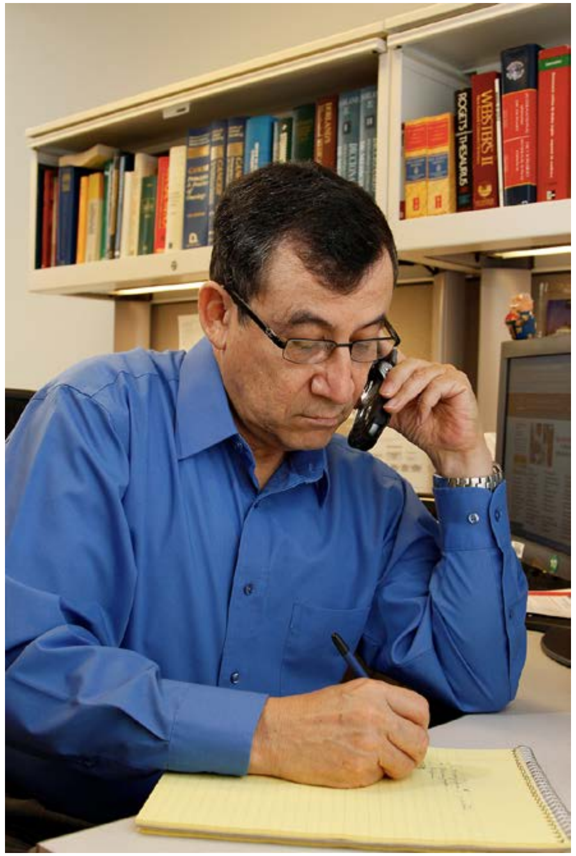


Crucial Elements for Planning

- Knowing the cancer situation (burden – incidence & mortality)
  - *Population census, demographic data*
  - *Cancer registries (population based or hospital if not available)*
- Knowing where gaps are (services, programs, policies)
  - *Vital statistics registries*
  - *Periodic surveys on risk factors (e.g., % smokers)*

Crucial Elements (continued)

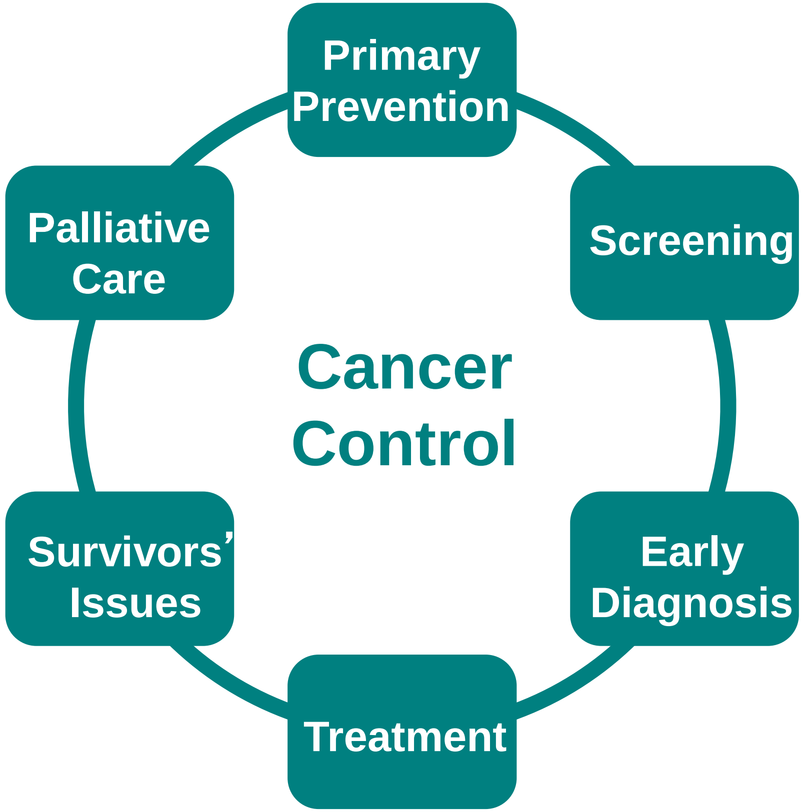
- Knowing how to address the gaps (evidence)
  - *Reports from programs, demonstration projects*
  - *Data from cancer control partners*
  - *Published articles*
  - *Capacity (i.e., policies, trained personnel, facilities, programs & services)*
- Knowing how you are doing (outcomes, progress)
  - *Cancer screening utilization monitoring systems*



Bruce Armstrong’s 6 x 9 Grid for Cancer Control

Each of the 6 domains of cancer control requires:

1. Basic Research
2. Situation Analysis
3. Intervention Development
4. Evaluation of Intervention
5. Awareness Raising
6. Program Planning
7. Program Implementation
8. Program Monitoring
9. Future Planning



Primary Prevention

Palliative Care

Screening

Cancer Control

Survivors’ Issues

Early Diagnosis

Treatment

Armstrong suggested that cancer registries are “central” to 34 of 54 elements of the grid and provide “support” for 9 additional elements.

Based on *Cancer Causes & Control* 3:569

Population-Based?

- Ability to systematically collect a record of data on all new cancer diagnoses occurring among residents of a geographically defined population

- To make sense of case counts of new cancer diagnoses we need data on the underlying population at risk for developing cancer

- Provides an unbiased picture of the cancer burden in the population and how it changes over time

Match Data to Your Needs

- No current national cancer plan?
  - Need data on the cancer situation
    - Burden
    - Infrastructure and policies
  - Use the data to assess gaps and decide what to do (i.e. what goes in cancer plan)

Image reproduced from Wired Magazine, 11/2014

Questions to Ask

- What data do we have?
  - Is it accurate, reliable?
- What other data do we need?
  - What is a feasible way to get it?
  - How can we build this into our cancer plan?
- Who can help us with data needs and use?
- Can we build data collection efforts into our basic plan for future planning and evaluation

International Agency for Research on Cancer

World Health Organization

GLOBOCAN 2012: Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012

You are here: **Home**

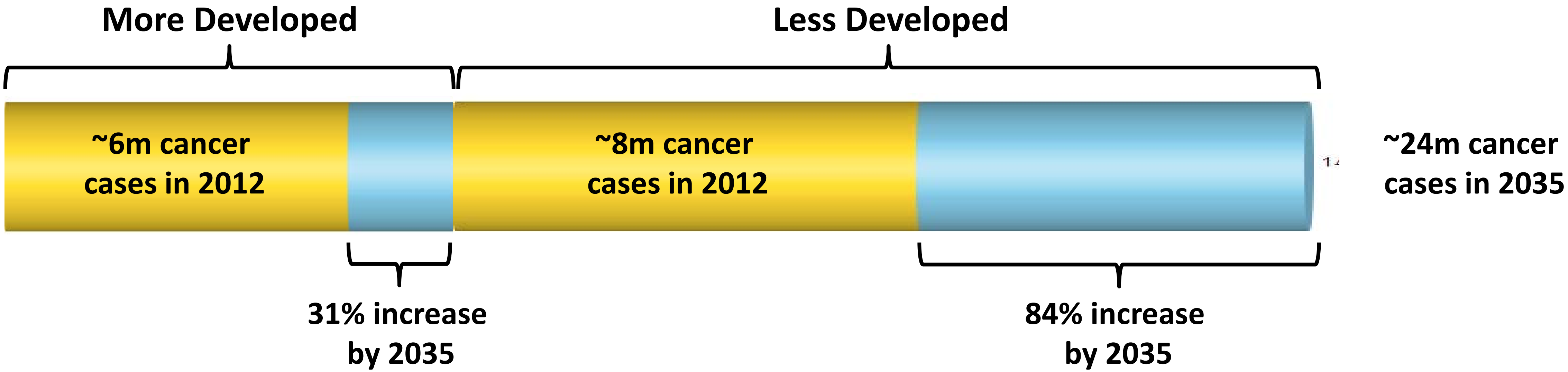
THE GLOBOCAN PROJECT

Welcome to the **GLOBOCAN** project. The aim of the project is to provide contemporary estimates of the incidence of, mortality and prevalence from major types of cancer, at national level, for 184 countries of the world. The GLOBOCAN estimates are presented for **2012**, separately for each sex. 1-, 3- and 5-year prevalence data are available for the adult population only (ages 15 and over). Please note that:

1. These estimates are based on the most recent data available at IARC and on information publically available on the Internet, but more recent figures may be available directly from local sources.
2. Because the sources of data are continuously improving in quality and extent, estimates may not be truly comparable overtime and **care should be taken when comparing these estimates with those published earlier**. The observed differences may be the result of a change in the methodology and should not be interpreted as a time trend effect.

GLOBOCAN has a “Predictions” Function

- GLOBOCAN allows projections of the future cancer burden based on predicted demographic changes (populations growing in number and average age using current age-specific risk).
- Projections can be made for individual countries or for the various aggregations of GLOBOCAN (e.g., regions or development stage)



More Developed

Less Developed

~6m cancer cases in 2012

~8m cancer cases in 2012

~24m cancer cases in 2035

31% increase by 2035

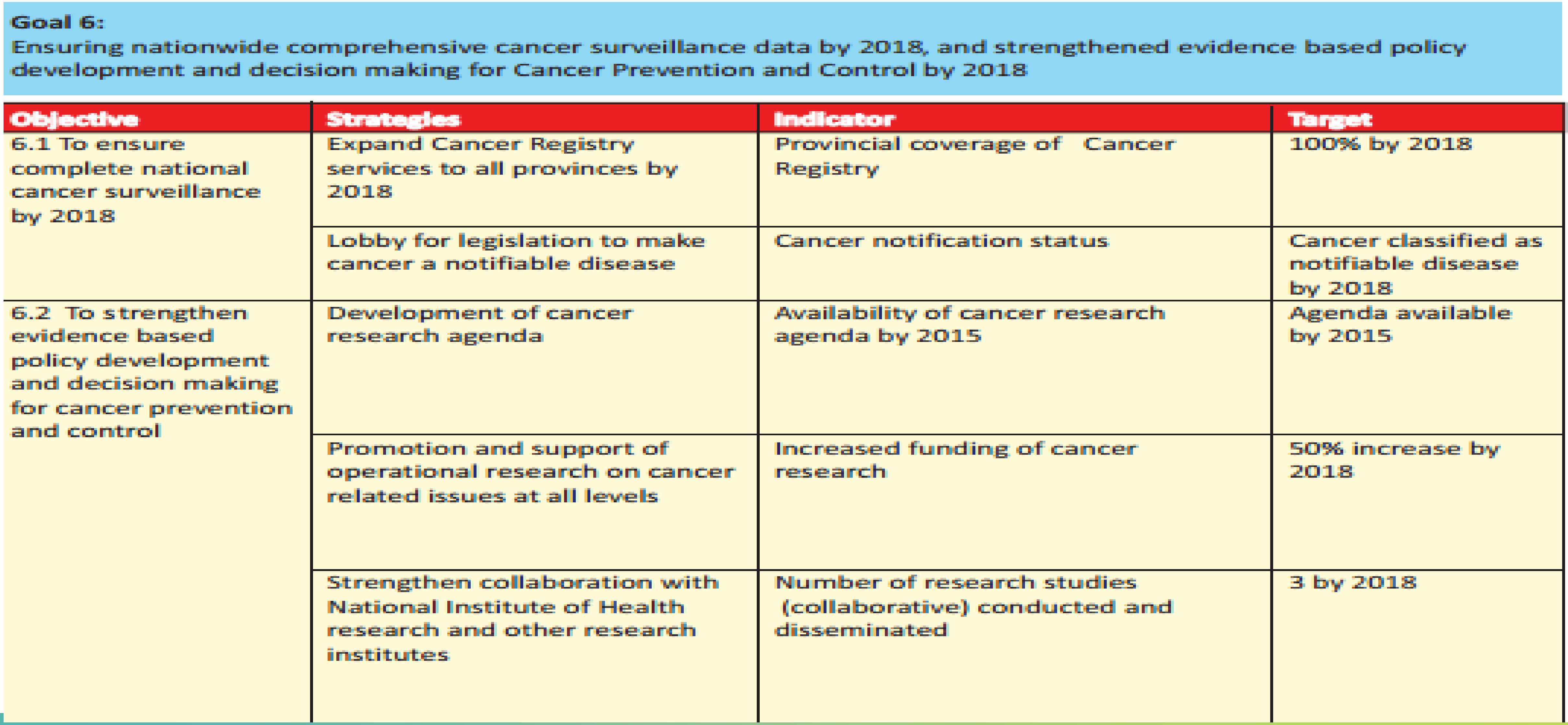
84% increase by 2035

Data: http://globocan.iarc.fr

Match Data to Your Needs

- Have a cancer plan already?
  - Use data related to cancer plan goals and objectives to monitor progress and make decisions about what to do next
  - Use data trends to identify new or emerging priorities your country might need to focus on

Improving Data:
Example Data Goal from a National Cancer Plan

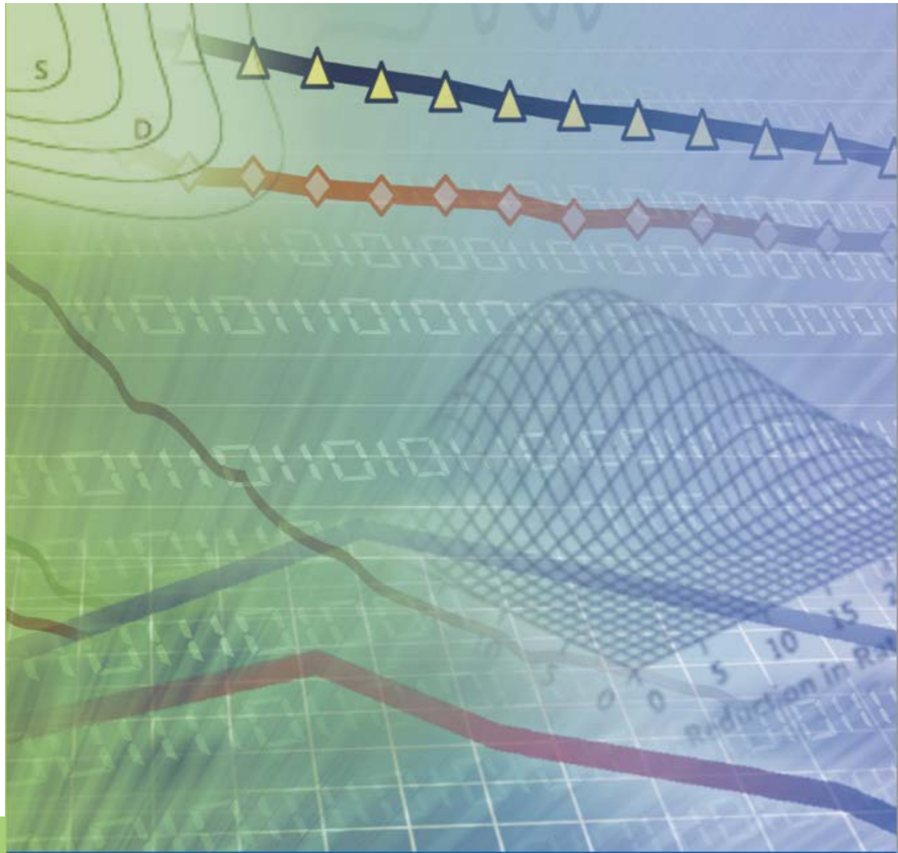


Goal 6:
Ensuring nationwide comprehensive cancer surveillance data by 2018, and strengthened evidence based policy development and decision making for Cancer Prevention and Control by 2018

Objective	Strategies	Indicator	Target
6.1 To ensure complete national cancer surveillance by 2018	Expand Cancer Registry services to all provinces by 2018	Provincial coverage of Cancer Registry	100% by 2018
	Lobby for legislation to make cancer a notifiable disease	Cancer notification status	Cancer classified as notifiable disease by 2018
6.2 To strengthen evidence based policy development and decision making for cancer prevention and control	Development of cancer research agenda	Availability of cancer research agenda by 2015	Agenda available by 2015
	Promotion and support of operational research on cancer related issues at all levels	Increased funding of cancer research	50% increase by 2018
	Strengthen collaboration with National Institute of Health research and other research institutes	Number of research studies (collaborative) conducted and disseminated	3 by 2018

Getting the data you need…

- A national cancer control plan can include strategies around:
  - Designing and developing new data surveillance systems
  - Strengthening existing systems



❷ Types and planning

What is cancer registration?

- The **registry** is the organization that is responsible for the collection, storage, analysis and interpretation of data on persons with cancer
- **Cancer registration** is the process of continued, systematic collection of data during a given time, period, and place
- Cancer registries and cancer surveillance provide the infrastructure and tools that are key for planning new initiatives (cancer control spectrum) and facilitating cancer research

Main types of cancer registries

➊ Population-based cancer registry (PBCR)

➋ Hospital-based cancer registry (HBCR)

➌ Pathology-based cancer registry

Pathology-based cancer registries - Characteristics

- Records from one or more laboratories on histologically diagnosed cancers, making the diagnosis often of high quality
- Purpose is to support the needs for laboratory-based services
- **Population from which the tumour tissues has come is not defined**

Hospital-based cancer registries (HBCR) - Characteristics

- Records from a particular hospital
  - Dependent on referrals
  - The population from which cases arise is NOT defined
- Information on cancer patients, treatment and results
- Purpose is administrative (forecasting service, equipment and HR), clinical performance and research
- Data is often more extensive vs PBCR

Population-based cancer registries (PBCR)

- To **collect and classify** information on **all cancer cases** in order **to produce statistics** on the occurrence in **defined populations**
    - Requires denominator data (population) to make sense of numerator data (case counts)
    - Foundation of cancer control planning and monitoring

PBCR - Characteristics

- Data from hospitals and non-hospital / multiple sources
- Identification of cases from a defined coverage area
  - Allows for the calculation of incidence rates
    - Assessment of current magnitude of cancer burden and future burden
    - Monitor the impact of interventions

PBCR – principles

The PBCR aims to record relevant information on all cases of cancer diagnosed within the target population.

Diagnosed: Start with a target population with access to diagnostic/treatment services.

Recorded: All cases are recorded - even if diagnosis based on clinical examination only.

Relevant information: ≈10 essential items recorded that relate to the patient and their diagnosis.

Target population: Critical to have reliable census-based estimates on the target population; without this information, impossible to accurately calculate/compare rates

Registry type	Characteristics	Purpose	Can this 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.** An incomplete and inaccurate sample. Dataset is based on patient attendance at given hospital(s).
Pathology-Based Cancer Registry	Collects information from one or more laboratories on morphologically-diagnosed cancers.	Supports need for laboratory-based services and serves as quick ‘snapshot’ of cancer profile.	**NO.** An incomplete and inaccurate sample. Dataset is based on laboratory-based surveillance only.
Population-Based Cancer Registry	Systematically collects information on all reportable neoplasms occurring in a geographically-defined population from multiple sources.	Supports population-based actions aimed at reducing the cancer burden in the community.	**YES.** Such a systematic ascertainment from multiple sources can provide an unbiased profile of the cancer burden and how it is changing over time.

● Establishing a Registry System

Priorities

- Obtain stakeholder support
  - Government
  - Medical Community
  - Advocates, Non-Governmental Organizations, Community
  - Cancer Control Plan Leadership, Other data users
  - Advisory Board

Define Target Population -“Big Picture”

Cancer registry

- must be able to capture information on new cancer cases *within* the target area
- must be able to identify residents from nonresidents
- should be able to capture information on cancer in residents diagnosed and/or treated *outside* the target area
- must be able to avoid counting the same case twice

Define Target Population

Target area

- must have available medical care and access to medical care so that cancer cases come in contact with the healthcare system
- must have systems for reporting both pathology and clinical data
- must have ability to exchange data with other areas residents may go for diagnosis and treatment
- must be able to identify nonresidents coming in for care

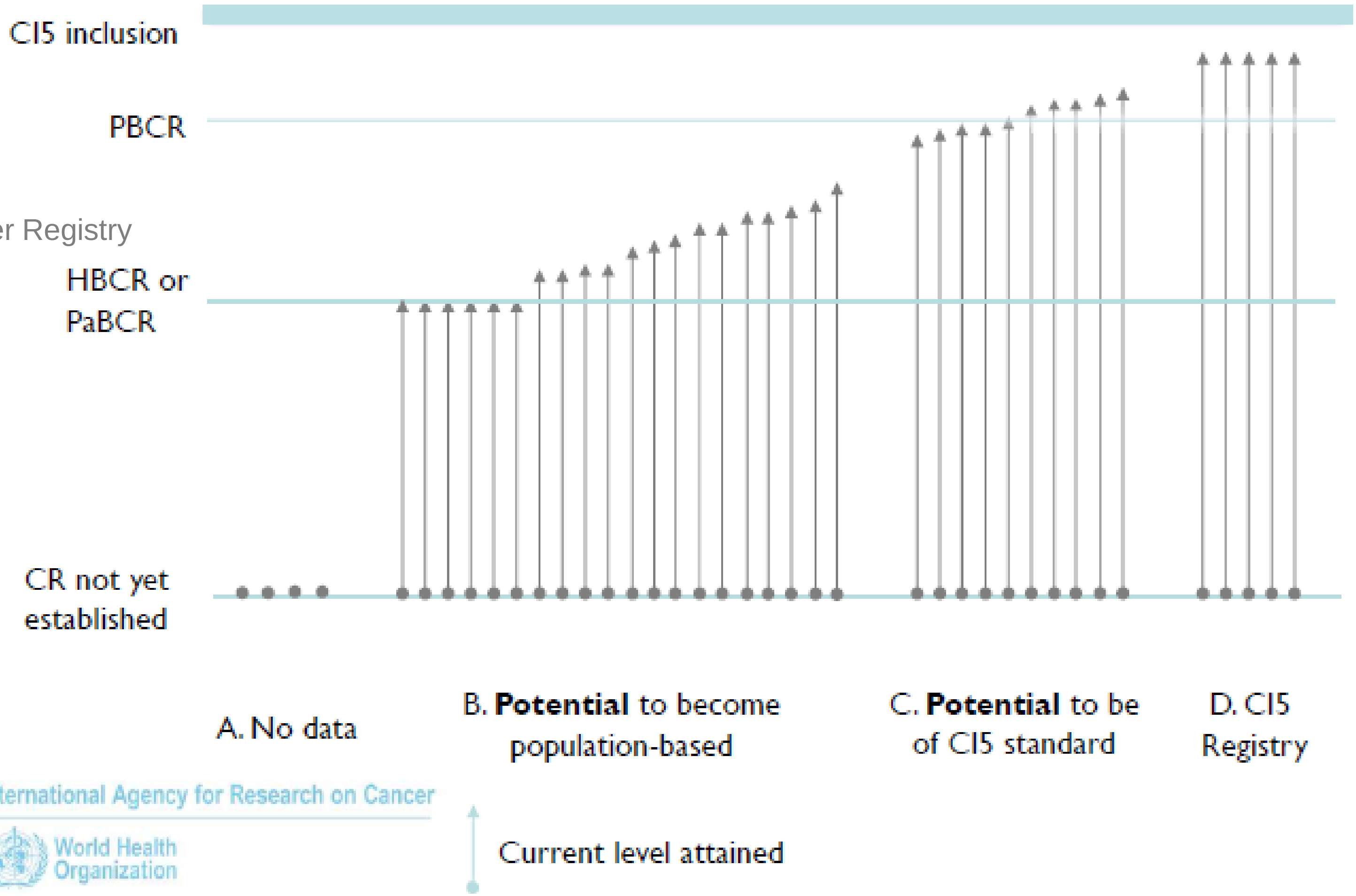
Define Target Population -“Key Decisions”

Important decisions must be made in regard to size of target population: local, regional, national, other

Guiding factors

- Feasibility (must be able to count cases properly)
- Ability to accurately measure size and composition
- Cost vs benefit
    - Ability for leaders to effectively monitor and plan
    - Ability to extrapolate results outside the target population as needed

Evolution of a Cancer Registry



Seek Access to Critical Data

- It is important to establish the legal authority for the operation of the cancer registry in the target population; cancer is a reportable disease
- Value: Provides some legal protection for data reporters and facilitates access to reporter’s facility
- Remember: requirement to report does not guarantee data completeness or data quality

●Develop and define data standards

The importance of partnerships, at the highest levels, to develop data standards can’t be overstated for population-based registries

Common standards (‘common language’) promote:

- consistency in data collection
- ease in data transmission / data sharing
- the ability to link and aggregate data
- comparability of data across registries
- developing technology to enhance quality & capture

Data Collection: Key Questions

- What data will be collected?
- How will the data be collected from data sources?
- How will the data be managed, analyzed and disseminated?

Basic Data

- Information to define a cancer to calculate incidence rates
    - Person: Name, date of birth, (race/ethnic group?)
    - Place: Address at diagnosis, resident/non-resident
    - Cancer: Primary site, histology/morphology, grade, laterality, date of diagnosis, how diagnosed (pathology/clinical)
- Other: Stage (extent of disease), date of death (annual vital status?), Death Certificate only cases, reporting source

System Support -

- Quality Control
- Benchmarks
    - *Cancer in Five Continents- IACR*
    - *Cancer in North America- NAACCR*
- Education
- Information Technology

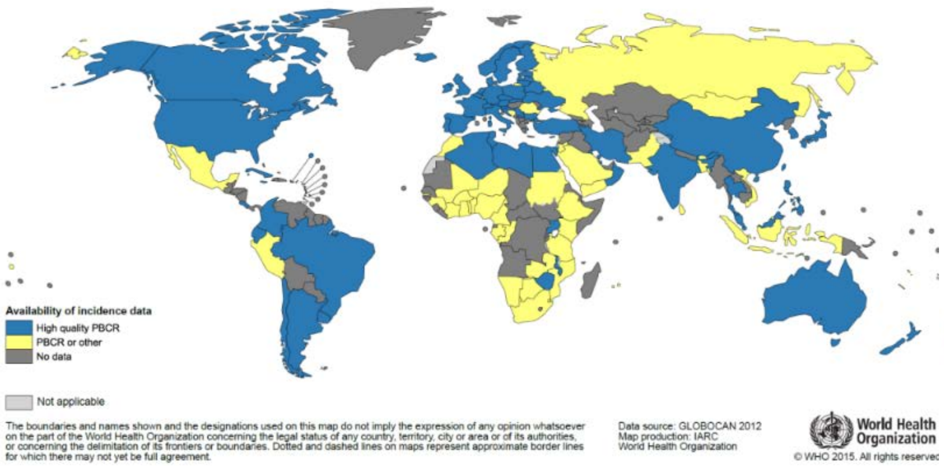
Finance

- Costs of cancer registration depend on:
  - Size and population of the registration area
  - Number and type of data sources
  - Number of data items collected
  - Data collection methods

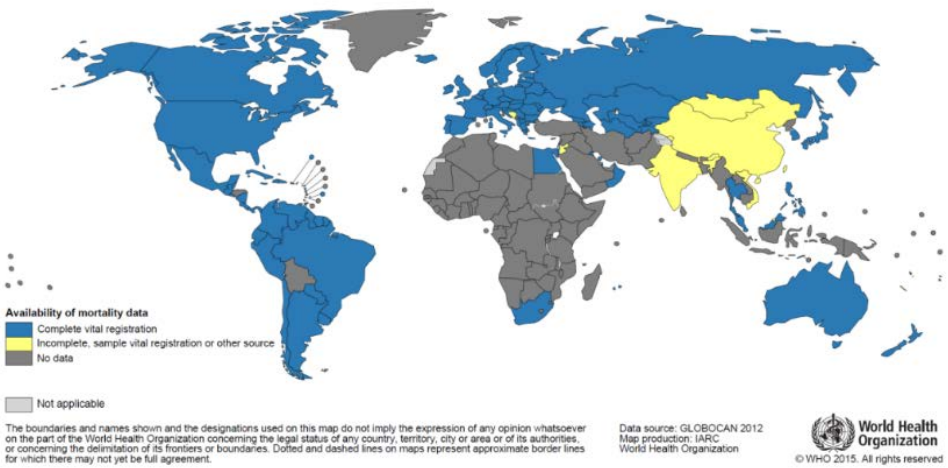
- Important to secure funds to sustain the registry for 3-5 years

❸ Key Challenges

Data availability: Worldwide



Data source: GLOBOCAN 2012
Map production: IARC
World Health Organization



Data source: GLOBOCAN 2012
Map production: IARC
World Health Organization

INCIDENCE **36 %**

MORTALITY **19 %**

Only 67 of 184 countries report high quality incidence data to IARC[1]

Only 34 of 178 countries report high quality mortality data to WHO[2]

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[1] *Cancer Incidence in Five Continents Volume X*

[2] WHO Mortality Database

Context

The establishment of good quality Cancer Registries is the function of the availability of Health Care System, its utilization and willingness of health care professionals to co-operate

Main challenges of cancer registration in developing countries

- Lack of Basic Health services
- Lack of stability of population
- Identity of individuals.
- Identification of residential status
- Non availability or incomplete medical records
- Lack of Trained personnel
- Retention of trained staff
- Lack of follow up
- Non-availability of census data
- Lack of data processing facilities
- Funding
- Medical apathy- non-cooperation from medical personnel

To overcome challenges

- Location of registry
- Private Hospital/cancer centers are part of project
- Identify sources of registration outside registry area.
- Permanency of registry staff
- Continuous training.
- Availability of software for data entry and analysis
- Dissemination of cancer registry report and publication of registry data in collaboration with clinicians

Medical apathy – Non cooperation

- Important to obtain cooperation but often difficult. May be due to medical apathy or confidentiality reasons

Possible solutions

- Formulate a Registry Steering Committee that includes clinicians from many sources
- Work with clinicians on publication of results from the registry.
- Obtain a letter of support from MOH

Non-compliance of symptomatic cases for diagnosis and treatment

Solution

- Regular motivation visits to the symptomatic patients every six months.

- Motivational efforts for the symptomatic patients through village leaders/ social workers

Support: The Global Initiative for Cancer Registry Development (GICR)

- First global strategy to improve in-country capacity to collect, analyse and communicate data to inform cancer control planning
- A flexible model to support over 150 countries through six regional IARC Hubs worldwide
    - Phased objectives to target 20 countries by 2020 and a further 30 by 2025

National Cancer Institute
at the National Institutes of Health

American Cancer Society

CDC
Centers for Disease Control and Prevention

International Association of Cancer Registries

IAEA | PACT Programme of Action for Cancer Therapy

INCTR
International Network for Cancer Treatment and Research

NAACCR
North American Association of Central Cancer Registries

Pan American Health Organization
Regional Office of the World Health Organization

RINC
Red de Institutos Nacionales de Cáncer
UNASUR

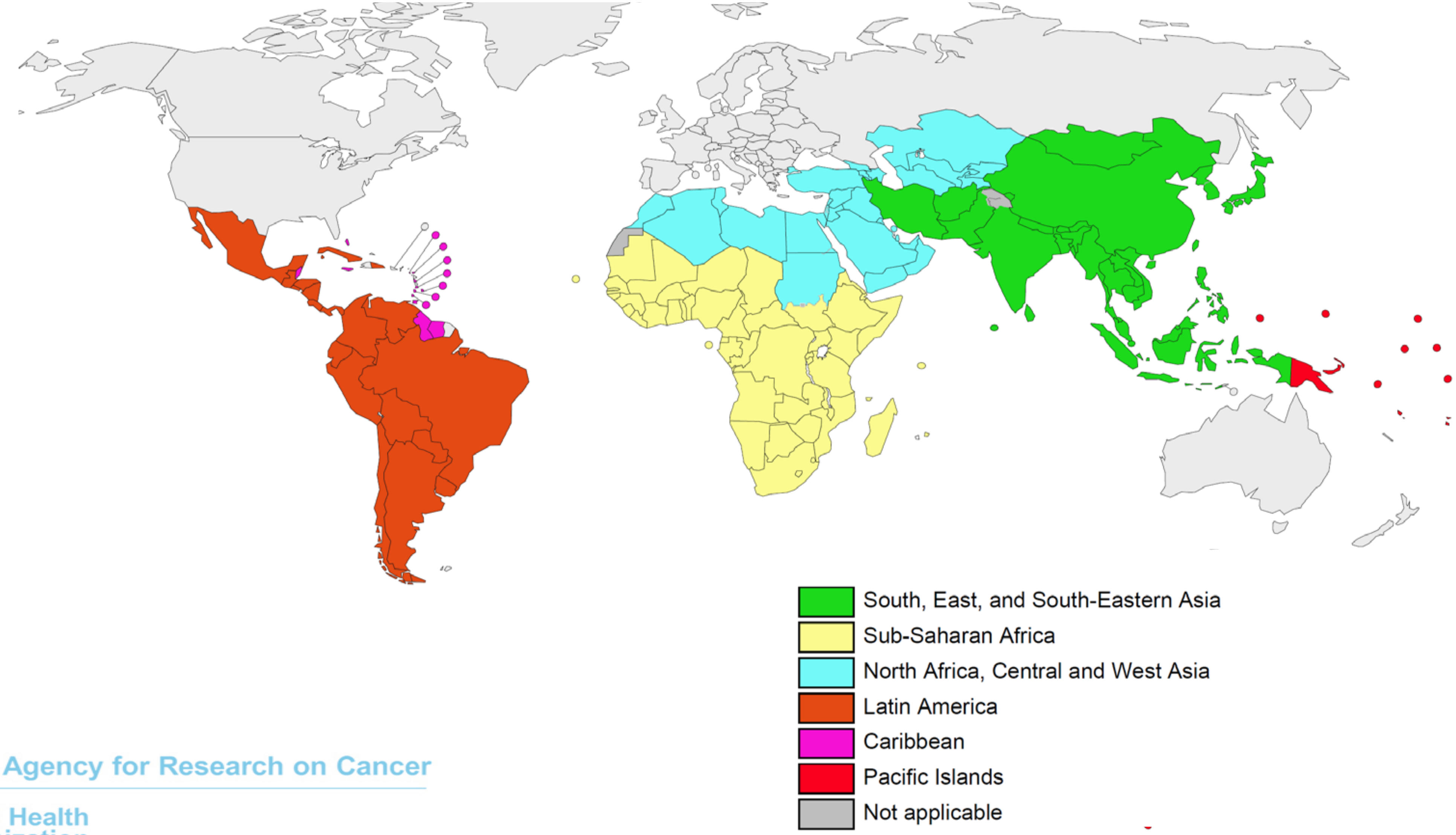
uicc
global cancer control

World Health Organization

and other national and international partners

GICR
Global Initiative for Cancer Registry Development
Initiative Mondiale pour le Développement des Registres du Cancer
Iniciativa Mundial para el Desarrollo de Registros de Cáncer

IARC Regional Hubs for Cancer Registration



Thank You!

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