Improving Cancer Registries through Enhanced Stakeholder Buy-in

What's in it for them?

Outline

1. Why cancer registries are important and how they relate to cancer control plans
2. Important stakeholders to engage and how to motivate them

What is a cancer registry?

- The **registry** is the organization that is responsible for the collection, storage, analysis and interpretation of data on persons with cancer

Main types of cancer registries

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.

Population-based cancer registries

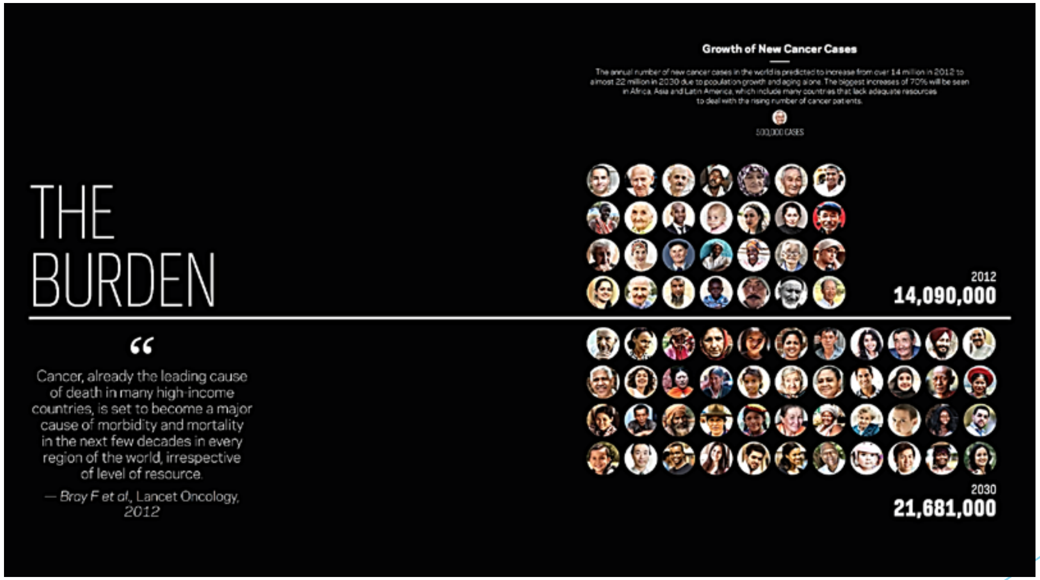
- Population-based cancer registries and cancer surveillance provide the infrastructure and tools that are key for planning and evaluating activities across the cancer control spectrum and facilitating cancer research
- Provide an unbiased picture of the cancer burden in the population and how it changes over time
- May be local (city), regional (county, province, state), or national
- The key is to collect information of EVERY case have underlying population data on the SAME area

Population-based cancer registries

- May be hosted by government agency (Ministry of Health), academic setting (University), but usually not in private setting. Partnerships may be necessary
- Must have legal authority to collect data on residents for public health purposes
- Must protect confidentiality – legal safeguards important

Why do we need cancer registries?

- Planners need timely data representing the true underlying cancer burden in their communities
- Population-based cancer registries are designed to provide this needed information



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.

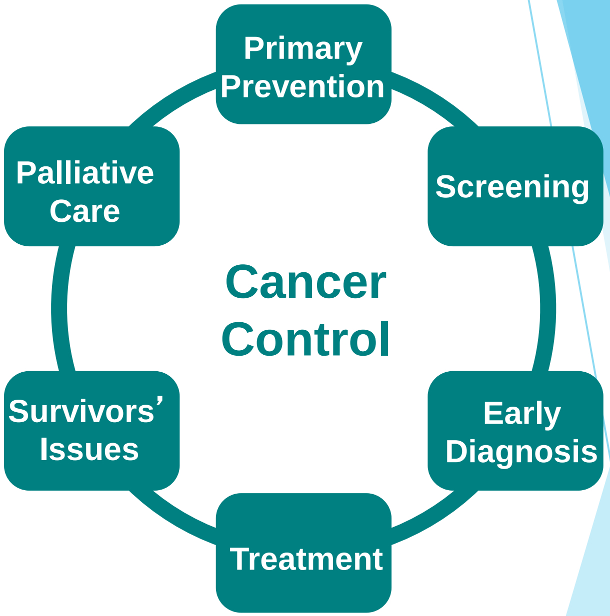
Source: World Cancer Atlas

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

Bruce Armstrong's 6X9 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



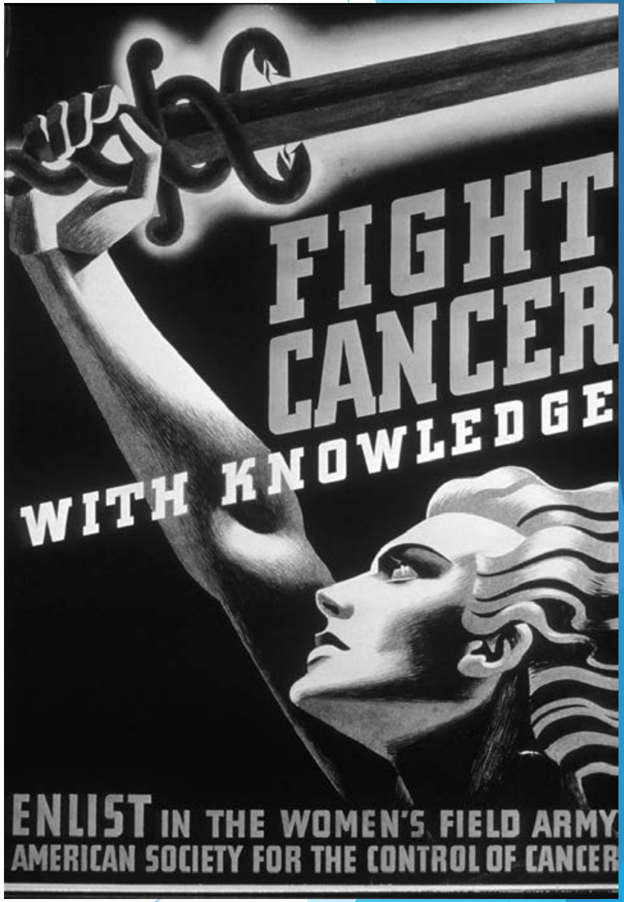
Armstrong suggested that cancer registries are "central" to 34 of 54 elements of the grid and provide "support" for 9 additional elements.

Based on *Cancer Causes & Control* 3:569

Specific uses for data in cancer control planning

- Develop cancer profiles
- Identify needs across the spectrum of cancer control activities

  Assess and monitor efforts
- Understand the potential impact of interventions/ make evidence based policy
- Motivate key partners to take action
- Health systems planning



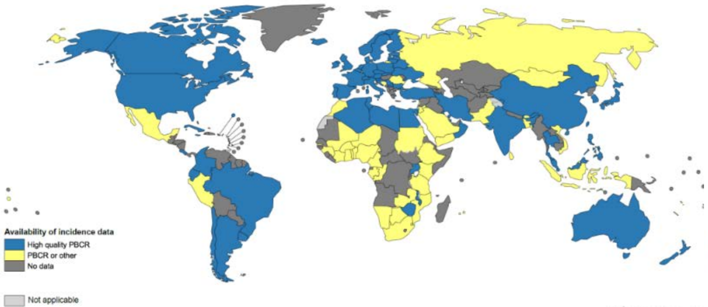
More uses for data in cancer control planning

- Determining the cancer burden
  - Identifying populations at risk
  - Cancer incidence rates in various populations/areas
  - Monitoring trends over time in these populations
  - Predicting future burden based on population specific data
  - Estimating prevalence and survival-long term trends

A key challenge

- As many of us know…just because you have a registry doesn’t mean the data will be:
  - Complete
  - High quality
  - Disseminated and used appropriately

Data availability worldwide



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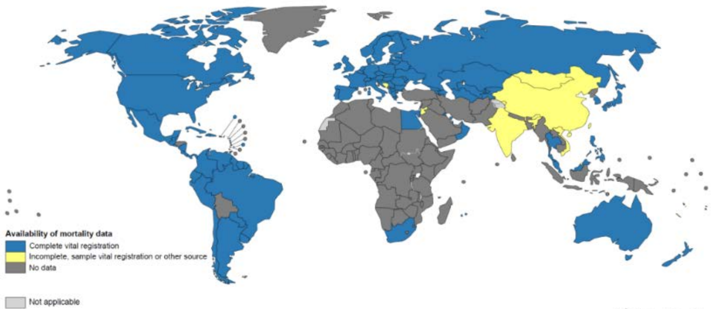
Data source: GLOBOCAN 2012
Map production: IARC
World Health Organization

World Health Organization



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World Health Organization

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]

[1] *Cancer Incidence in Five Continents Volume X*
[2] WHO Mortality Database

Components of the challenge

The establishment of good quality cancer registries is the function of the availability of a health care system, its utilization, and **the willingness of health care professionals (and others) to cooperate**

- Some of these challenges are systemic, related to the basic underlying infrastructure for health care delivery
- Some can be addressed by education, collaboration, and sharing of information
- **Some can be addressed by building relationships with key individuals and organizations**

Who are the key stakeholders?

- Health policymakers
- Public
- Legislators
- Program planners
- Care providers
- Advocates
- Researchers

What do they typically contribute?

- Civil society & public – advocacy and getting evidence-based messages out
- Legislators – funding, legal authority (e.g. to make cancer a reportable disease)
- Health policymakers and program managers – funding, staff, office space
- Researchers and registry personnel – registry expertise and implementation
- Care providers and hospital staff – data collection and reporting

Important information from registries that stakeholders care about (What's in it for them?)

- Information on cancer burden
- Community/sub-national profiles
- Planning information for cancer control activities
- Evaluation of success of cancer control programs (e.g. screening program)
- Health systems planning information

How can this information help the stakeholder groups?

Information on cancer burden

- **Uses**
  - Identifying populations at risk
  - Cancer incidence rates in various populations/areas
  - Monitoring trends over time in these populations
  - Predicting future burden based on population specific data
  - Estimating prevalence and survival- long term trends
- **Who the information helps**
  - Health policymakers and program planners
  - Legislators
  - Care providers
  - Researchers
  - Civil society and public

Community/sub-national profiles

- **Uses**
  - Data from cancer registry and health behavior patterns used to assess community
  - Define local cancer priorities based on data
  - *Examples: Locate pockets of high cervical cancer rates, or late stage breast or colon cancers*

- **Who the information helps**
  - Health policymakers and program planners
  - Legislators (local)
  - Care providers
  - Researchers
  - Civil society and public

Planning information for cancer control activities

- **Uses**
  - Data from community profiles used to target populations and areas with greatest need
  - Supports EVIDENCE-BASED DECISION MAKING
  - Allows for targeting of resources to meet specialized needs of a community

- **Who the information helps**
  - Health policymakers and program planners
  - Care providers
  - Civil society and public

Evaluation of success of cancer control programs

- **Uses (measured over time)**
  - Decline in cancer rates (e.g. colon cancer)
  - Increase in cancer rates due to early detection (e.g. breast, prostate)
  - Increase in early stage cancers and decline in late stage cancers
  - Changes in mortality rates
  - Long term trends may be seen eventually (e.g. smoking cessation resulting in lung cancer decline)
- **Who the information helps**
  - Health policymakers and program planners
  - Legislators
  - Care providers
  - Researchers
  - Civil society and public

Health systems planning information

- **Uses**
  - Provides info on need for:
    - number of cancer hospital beds
    - radiation therapy facilities
    - laboratories
    - chemotherapy clinics
    - rehabilitation, physical therapy, & occupational therapy clinics
    - psychosocial and support services
- **Who the information helps**
  - Health policymakers and program planners
  - Legislators
  - Care providers
  - Researchers
  - Civil society and public

More information on each stakeholder group

- How do they use the information to do their jobs better and get better outcomes?
- ✓ What are their specific roles in improving completeness, quality, and appropriate use of data?

Policymakers and civil society/advocacy

- ▪ Shaping policy for improved public health, lower rates of disease, and longer life
- ✓ Need to understand the burden of cancer
- ✓ Need numbers and rates to make factual decisions about priorities
  - Number of new cancers, cancer incidence and mortality rates, number of deaths, number of people living with cancer
  - Information on risk factors, behaviors, and demographics to predict future trends
  - Local data to determine where to invest scarce resources for the greatest effect

The public

- Understand the burden of cancer and risk factors
    - ✓ Modify behaviors
    - ✓ Participate in screening and early detection
    - ✓ Know if cancer is going up or down
- Cancer rates and trends
- Survival statistics

Care providers and the medical community

- Improved diagnosis and care
- ✓ Understand what types of cancer are more common in the community
- ✓ Understand patterns of cancer risks in sub-groups of the population
- ✓ Understand risk and screening behaviors
- ✓ Knowledge of cancer control programs – refer patients for screening and other interventions
- ✓ Understand requirements for reporting cancers - how much time and effort required
- ✓ Collect data and report
- ✓ Requirements for implementing other aspects of cancer control plan

Legislators and other elected officials

- Basic data and understanding of the cancer burden
- Understanding of cancer surveillance and cancer control
- Provides basis for legislative action
  - ✓ Legislation making cancer reportable disease
  - ✓ Legislation for improved mortality data collection
  - ✓ Legislation for reducing cancer risks (tobacco control)
  - ✓ Funding of Registry and Cancer Control Plan
  - ✓ Funding of public resources dedicated to the diagnosis and treatment of cancer

Program planners and hospital leadership

- Expected patient numbers
- Expected financial costs and income from providing services
- Market share – ability to attract patients
- ✓ Plan of major investments for cancer care: hospitals, specialty treatment centers, clinics, cancer-related services
- ✓ Purchase supplies, medications, other cancer-related expenses
- ✓ Plan for medical services - medical personnel, staff, clinics, etc.

Researchers

- ✓ Study unusual patterns of cancer (e.g. genetic factors in previously unstudied populations)
- ✓ Identify risk factors
- ✓ Test local beliefs and questions
- ✓ Collaborate with other researchers on global issues
- ✓ Test effectiveness of cancer control initiatives and interventions on local scale

How to get started

- No Cancer Plan? No Cancer Registry
  - Find local advocates and supporters
  - Use data to make your case
  - Identify resources that can help you get started
  - Identify mentors

Image reproduced from Wired Magazine, 11/2014

Ask questions

- 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

Obtain stakeholder support

- Registry Director – individual to take responsibility for the registry and work together with other stakeholders
- Ministry of Health – leaders invested in using the data for cancer control activities
- Clinicians – pathologists and oncologists (surgical, medical and radiation) involved in patient care
- Hospital Directors – leaders of the major reporting sources in the target population
- Local Health Leaders – leaders with access to specialized data needed for the target population

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

Use existing resources

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

You are here: **Home**

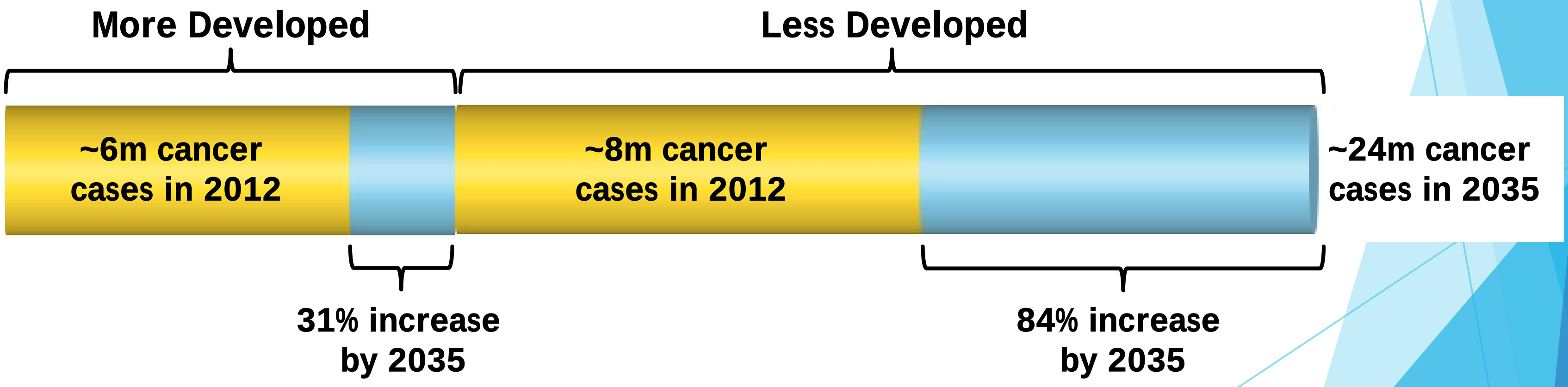
THE GLOBOCAN PROJECT

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

However…

- GLOBOCAN predictions are estimates based on pooled data
- Data may be sparse or unstable for certain areas
- Your area may not resemble the areas on which the GLOBOCAN estimates are based
- Your population may be changing in ways different from those used in GLOBOCAN assumptions (birth rates, death rates, immigration)
- Data from your own country will reflect the local burden in your population and will be more meaningful

Many challenges remain

- Lack of basic health services
- Lack of stability of population
- 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
- No mortality data

It's hard work…but it pays off

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

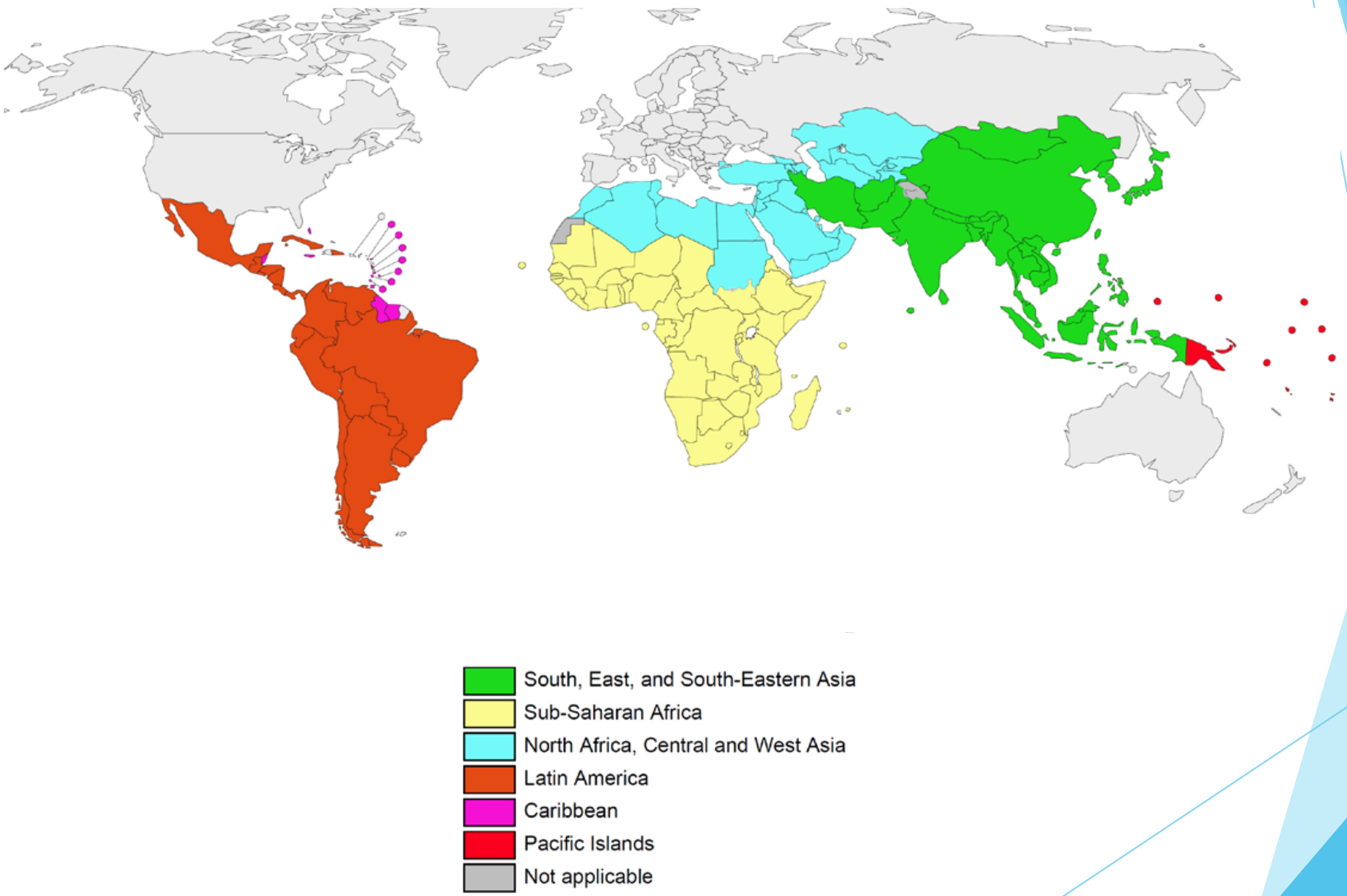
- First global strategy to improve in-country capacity to collect, analyse and communicate data to inform cancer control planning
- A flexible model to support over 150 countries through six regional IARC Hubs worldwide
    - Phased objectives to target 20 countries by 2020 and a further 30 by 2025

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
Programme of Action for Cancer Therapy
PACT
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 DEVELOPPEMENT DES REGISTRES DU CANCER
INICIATIVA MUNDIAL PARA EL DESARROLLO DE REGISTROS DE CÁNCER

GICR Regional Hubs for Cancer Registration



Resources

- International Association of Cancer Registries http://www.iacr.com.fr/
- Global Initiative for Cancer Registry Development http://gicr.iarc.fr/
- North American Association of Central Cancer Registries www.naaccr.org