Monitoring and Evaluation of a National Cancer Control Plan

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Data are the Heart of National Cancer Control Plan

- Pre-planning- Making the Case for a Cancer Control Plan
- Planning- What are our priorities? Where can we make the most impact?
- Monitoring- How are we doing? Do we need to change strategies?
- Evaluating- Did we accomplish our goals? How do we improve? What's next?

Why are Data Important?

- Supports evidence-based decision making
  - Allows for targeting of resources to meet specialized needs of a community
  - Policy needs to be based on DATA – not whims
- Shapes policy for improved public health, lower rates of disease, and longer life
- 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

Purpose and Uses of Data in Cancer Control

- Determining the Burden of Cancer
  - Assessing the problem
- Who is at risk of developing Cancer
    - Community profiles
- Planning cancer control initiatives
  - Where should we plan interventions (screening, smoking cessation, diet)

More Uses of Data for Cancer Control

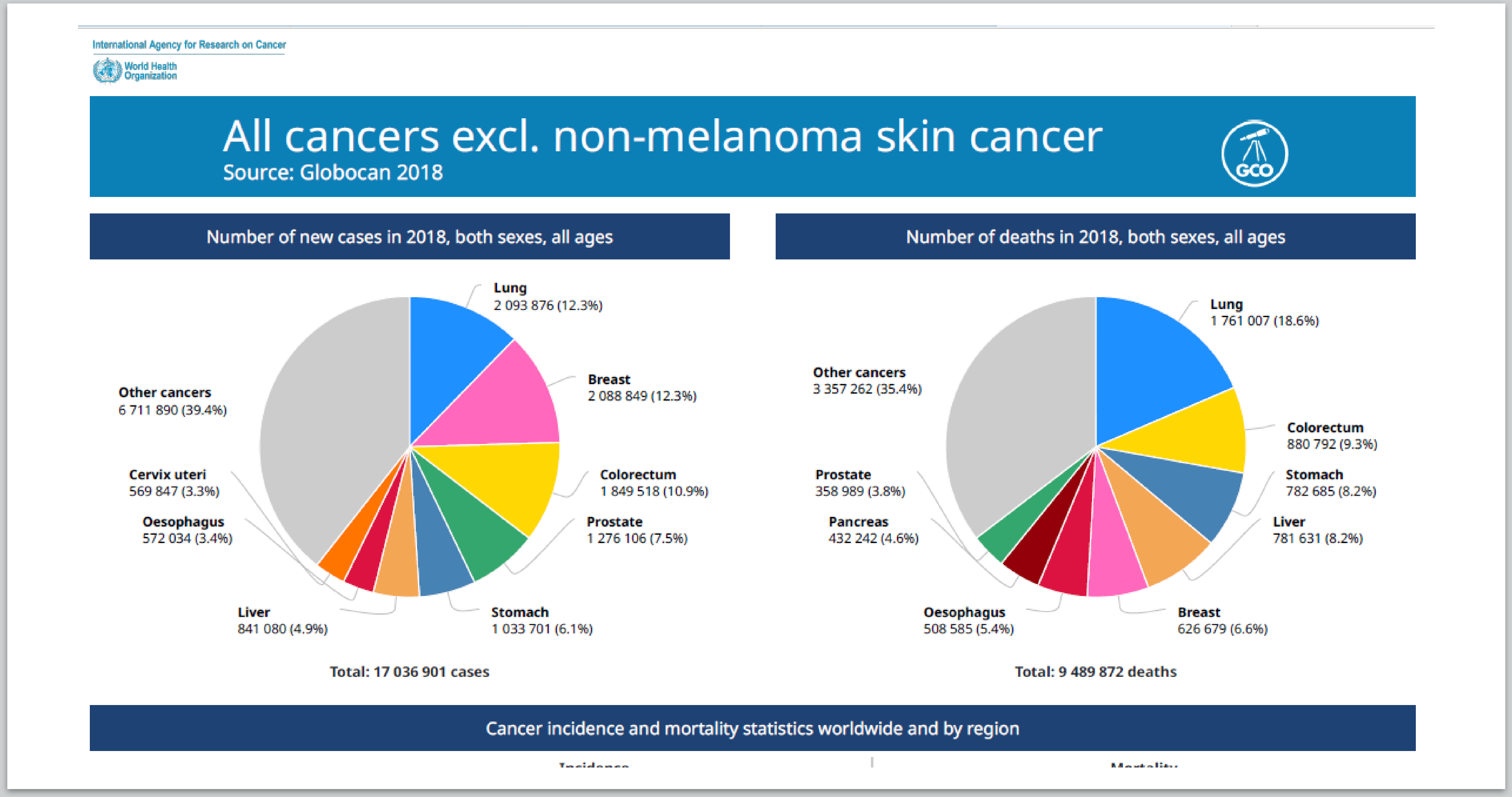
- Monitoring progress
  - Vaccination data
  - Number of persons screened and outcomes
  - New policies
  - Tobacco sales/use
- Evaluating success of cancer control programs
  - Monitoring incidence
    - Increase or decrease
  - Monitoring mortality
    - Decrease
  - Monitoring stage at diagnosis
    - Toward earlier stage

What is a Population-based Cancer Registry?

Organization charged with collecting a record of data for **every individual** with a **new diagnosis of cancer** during a **given time period** and within the geographic boundaries of a **specified place**

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



International Agency for Research on Cancer

World Health Organization

All cancers excl. non-melanoma skin cancer

Source: Globocan 2018

GCO

Number of new cases in 2018, both sexes, all ages

Lung
2 093 876 (12.3%)

Breast
2 088 849 (12.3%)

Colorectum
1 849 518 (10.9%)

Prostate
1 276 106 (7.5%)

Stomach
1 033 701 (6.1%)

Liver
841 080 (4.9%)

Oesophagus
572 034 (3.4%)

Cervix uteri
569 847 (3.3%)

Other cancers
6 711 890 (39.4%)

Total: 17 036 901 cases

Number of deaths in 2018, both sexes, all ages

Lung
1 761 007 (18.6%)

Colorectum
880 792 (9.3%)

Stomach
782 685 (8.2%)

Liver
781 631 (8.2%)

Breast
626 679 (6.6%)

Oesophagus
508 585 (5.4%)

Pancreas
432 242 (4.6%)

Prostate
358 989 (3.8%)

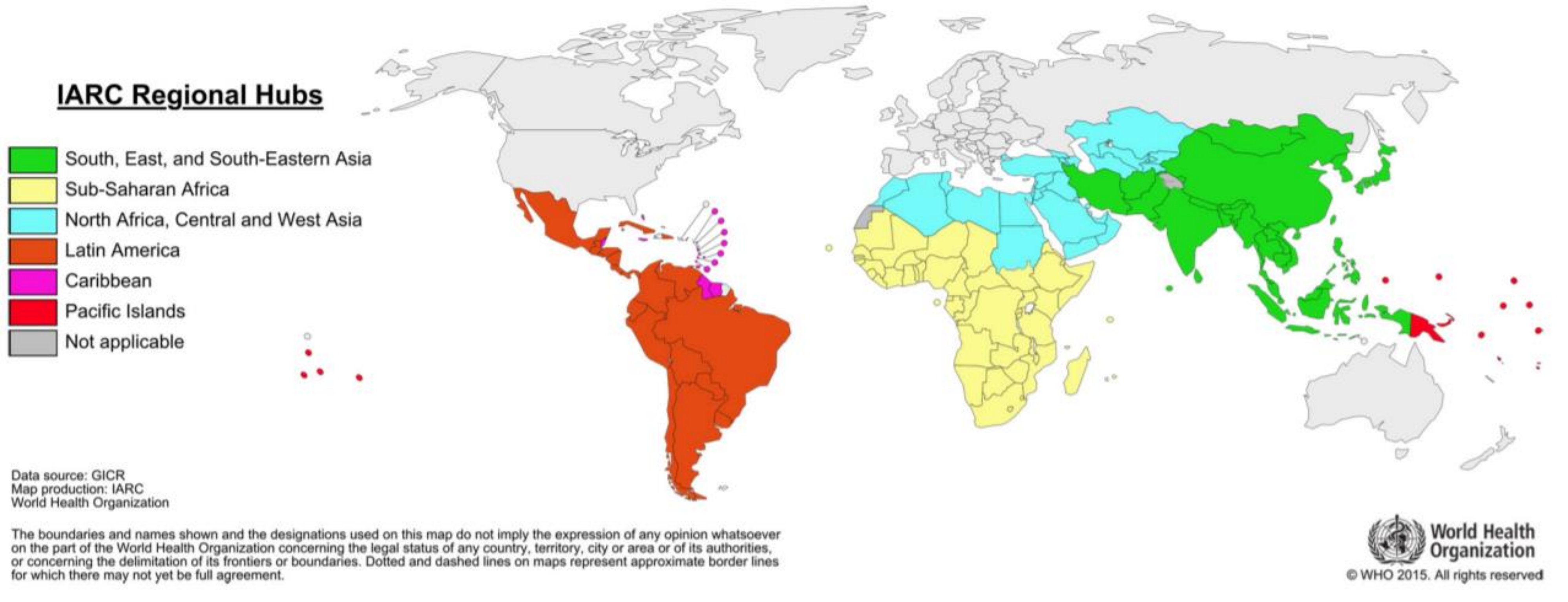
Other cancers
3 357 262 (35.4%)

Total: 9 489 872 deaths

Cancer incidence and mortality statistics worldwide and by region

Incidence | Mortality

Map of IARC Regional Hubs



Data source: GICR
Map production: IARC
World Health Organization

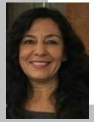
The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers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

World Health Organization

IARC REGIONAL HUB FOR CANCER REGISTRATION
MUMBAI

IARC REGIONAL HUB FOR CANCER REGISTRATION
SUB-SAHARAN AFRICA

IARC REGIONAL HUB FOR CANCER REGISTRATION
IZMIR



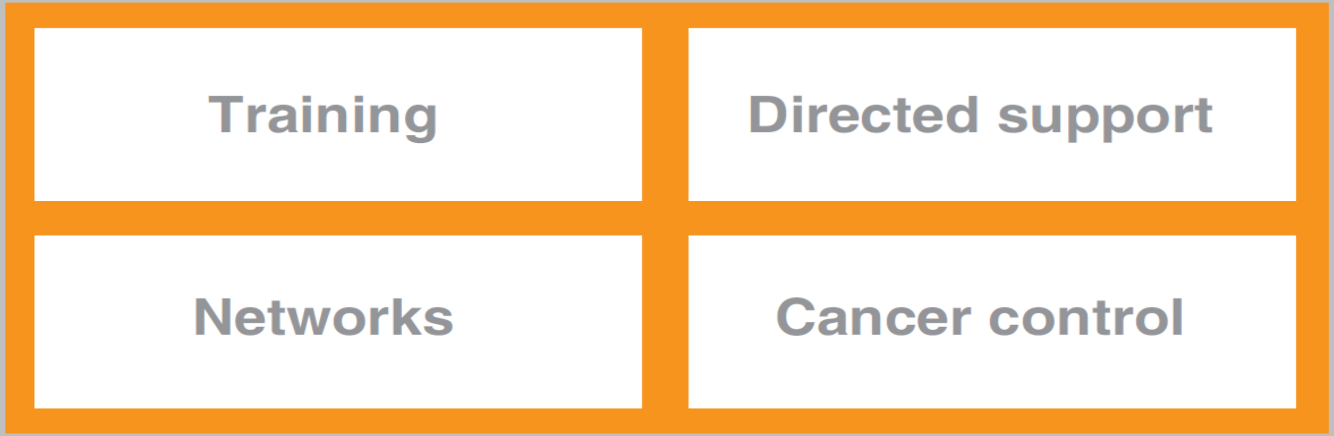
IARC REGIONAL HUB FOR CANCER REGISTRATION
LATIN AMERICA

IARC REGIONAL HUB FOR CANCER REGISTRATION
CARIBBEAN

IARC Regional Hubs: Functions

- Delivery of basic/advanced courses
- Development of accompanying resources

- Site visits to review practices
- Consultancy and mentorship to resolve specific issues



Training

Directed support

Networks

Cancer control

- Foster relationships between disciplines
- Provide information on upcoming activities

- Support cancer control interventions
- Stimulate research

Other Data to Consider

- Age Structure of the Population
  - Proportion of Elderly
- COVID -What is affect of COVID on population?
  - Delay in diagnosis?
  - Late stage disease?
  - More complications?
- Children
  - Fewer cases but societal burden is large
  - Planning for long-term effects

Who Else Needs Data?

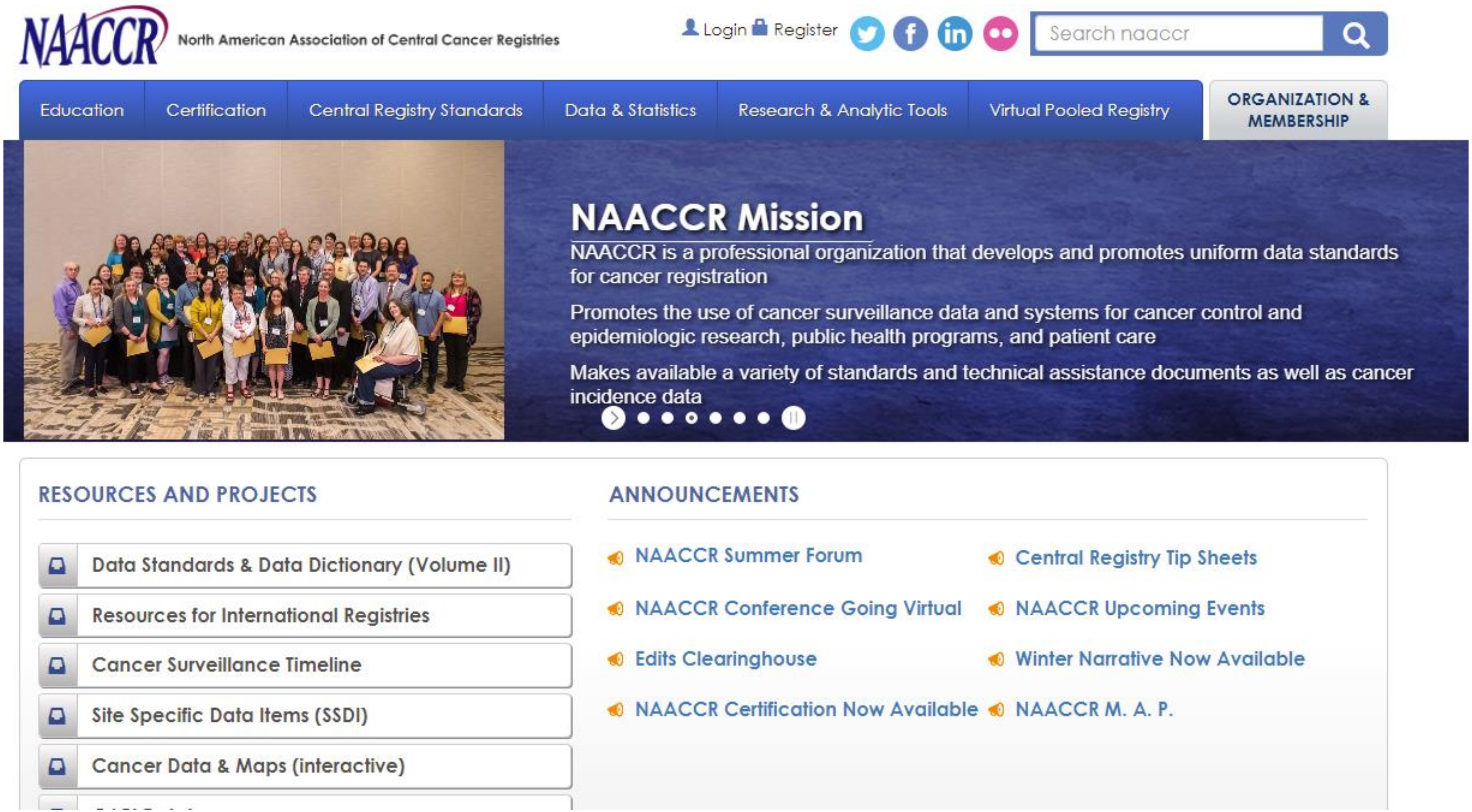
- The Public
  - Understand the burden of cancer
    - Modify behaviors
    - Participate in screening and early detection
    - Know if cancer is going up or down
    - Survival statistics
- Law Makers
  - Provides basis for legislative action
    - Making cancer reportable disease
    - Improved mortality data collection
    - Reducing cancer risks (tobacco control)
    - Funding of Registry and Cancer Control Plan
    - Funding of public resources dedicated to the diagnosis and treatment of cancer

Who Else needs data?

- Health Care Planners
  - Investments for cancer care: hospitals, specialty treatment centers, clinics, cancer-related services
  - Purchasing of supplies, medications, cancer-related expenses
  - Planning needs for medical services- medical personnel, staff, clinics, etc.
  - Financial costs and expected income from providing services
- Researchers
  - Study unusual patterns of cancer – 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

Coming soon:

- On-line study courses for international cancer registries on NAACCR Website
- www.naaccr.org
  - Module 1: Registry Operations – March 2022
  - Module 2: Data Quality- June 2022



NAACCR Mission

NAACCR is a professional organization that develops and promotes uniform data standards for cancer registration

Promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care

Makes available a variety of standards and technical assistance documents as well as cancer incidence data

RESOURCES AND PROJECTS

- Data Standards & Data Dictionary (Volume II)
- Resources for International Registries
- Cancer Surveillance Timeline
- Site Specific Data Items (SSDI)
- Cancer Data & Maps (interactive)

ANNOUNCEMENTS

- NAACCR Summer Forum
- NAACCR Conference Going Virtual
- Edits Clearinghouse
- NAACCR Certification Now Available
- Central Registry Tip Sheets
- NAACCR Upcoming Events
- Winter Narrative Now Available
- NAACCR M. A. P.

Summary

- Data are needed for all phases of Cancer Control Planning
- A wide variety of data can be used
- Population based cancer registries are useful in all phases
- Resources are available

Questions?

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www.naaccr.org