Improving Data for Decisions in Cervical and Breast Cancer Screening Programs in the Region and Regional Cancer Registry Hub

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Office of International Cancer Control

World Cancer Congress: Advancing cancer prevention and early detection in Latin America and the Caribbean through regional collaboration
Nov 3, 2016
No conflicts
National Breast and Cervical Cancer Early Detection Protection Program
NBCCEDP funds all 50 states, the District of Columbia, 5 U.S. territories, and 11 American Indian/Alaska Native tribes or tribal organizations.

National Comprehensive Cancer Control Program
NCCCP supports 50 states, the District of Columbia, 7 tribal groups, and 7 U.S. Associated Pacific Islands/territories.

National Program of Cancer Registries
NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the U.S. Pacific Island Jurisdictions.

Colorectal Cancer Control Program
CRCCP funds 24 state health departments, 6 universities, and one American Indian tribe.

What CDC is Doing in Cancer in the United States?
CDC and cancer screening programs since 1990s

1990

Organized Cancer Screening Programs

2005

Colorectal cancer Screening Demonstration

2009

Colorectal Cancer Control Program

2010

The Affordable Care Act is a unique opportunity for prevention.

2014 & beyond
# Quality Indicators for Program Performance

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Target</th>
<th>PY 2013 Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammography screening age 50 and older</td>
<td>&gt; 75%</td>
<td>84.8%</td>
</tr>
<tr>
<td>Women rarely/never screened for cervical cancer</td>
<td>&gt; 20%</td>
<td>34.5%</td>
</tr>
<tr>
<td>Breast diagnosis completed</td>
<td>≥ 90%</td>
<td>95.8%</td>
</tr>
<tr>
<td>Breast diagnosis completed within 60 days</td>
<td>≥ 75%</td>
<td>93.6%</td>
</tr>
<tr>
<td>Cervical diagnosis completed</td>
<td>≥ 90%</td>
<td>93.7%</td>
</tr>
<tr>
<td>Cervical diagnosis completed with 90 days</td>
<td>≥ 75%</td>
<td>88.3%</td>
</tr>
<tr>
<td>Breast treatment initiated</td>
<td>≥ 90%</td>
<td>98.0%</td>
</tr>
<tr>
<td>Breast treatment initiated within 60 days</td>
<td>≥ 80%</td>
<td>92.5%</td>
</tr>
<tr>
<td>Cervical treatment initiated</td>
<td>≥ 90%</td>
<td>93.3%</td>
</tr>
<tr>
<td>Cervical treatment initiated within 60 days (Invasive)</td>
<td>≥ 80%</td>
<td>91.3%</td>
</tr>
<tr>
<td>Cervical treatment initiated within 90 days (CIN2/3)</td>
<td>≥ 80%</td>
<td>94.2%</td>
</tr>
</tbody>
</table>
Program Effectiveness

**Conclusion:**
“Women screened by the NBCCEDP received diagnostic follow-up and initiated treatment within pre-established program guidelines.”

Richardson L et al. Timeliness of Breast Cancer Diagnosis and Initiation of Treatment. AJPH. 2010

IMPROVING DATA FOR DECISION-MAKING IN GLOBAL CERVICAL CANCER PROGRAMMES (IDCCP)

Toolkit for Monitoring and Evaluation, Surveys, and Costing Analysis
IDCCP Toolkit Introduction
WHY IMPROVE DATA?

* Collect the Data Needed
* Use Data that are Collected

Understand Disease Burden
Cost & Plan Programs

Improve Quality of Services
Show Impact

Estimate Coverage
Share Knowledge and Best Practices

To Save Lives
<table>
<thead>
<tr>
<th>How to identify opportunities for strengthening country data and data systems?</th>
<th>Part 1: Cervical Cancer Data and Data Systems Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to routinely monitor patients and programmes?</td>
<td>Part 3: Cervical Cancer Patient &amp; Programme Monitoring</td>
</tr>
<tr>
<td>How to survey facilities for service readiness, service availability, service quality?</td>
<td>Part 4: Facility-based Surveys for Cervical Cancer</td>
</tr>
<tr>
<td>How to estimate and analyse costs of cervical cancer screening &amp; treatment programmes?</td>
<td>Part 5: Cervical Cancer Prevention and Control Costing – Screening and Treatment Module</td>
</tr>
</tbody>
</table>

IMPROVING DATA FOR DECISION-MAKING IN GLOBAL CERVICAL CANCER PROGRAMS – APEC WORKSHOP
Scope of IDCCP Toolkit

Facilitators and Barriers to Care

- **Knowledge, Awareness, Beliefs**
  - (Data Systems, Pop and Fac Surv)

- **Access to Services**
  - (Data systems and Fac Surv)

Clinical Services for Cervical Cancer

- **Primary Prevention**
  - (Data Systems, Pop Surv)

- **Secondary Prevention**
  - (Full IDCCP Toolkit)

- **Cancer Treatment**
  - (Data Systems and Costing Analysis)

- **Palliative Care**
  - (Data Systems and Costing Analysis)

Measures of Health Impact

- Cervical cancer incidence rate
- Stage of cancer at first diagnosis
- Mortality rate from cervical cancer
IMPROVING DATA FOR DECISION-MAKING IN GLOBAL CERVICAL CANCER PROGRAMS – APEC WORKSHOP

1. Data Systems Assessment Implementation
   (Botswana, Kenya, Zambia, Ethiopia, and Guatemala)

   CDC Division of Global HIV/AIDS and TB

2. Development of the IDCCP Toolkit
   Part 1: Data Systems Assessment
   CDC Division of Global HIV/AIDS and TB

   Part 2: Population-based Survey Modules
   CDC Division of Cancer Prevention and Control

   Part 3: Facility-based Surveys
   CDC Division of Global HIV/AIDS and TB

   Part 4: Patient and Programme Monitoring
   CDC Division of Global HIV/AIDS and TB

   Part 5: Programme Costing Analysis
   George W. Bush Institute

3. Development of Products for Targeted Dissemination
   Web-based Knowledge Management
   George W. Bush Institute

   Outcomes Evaluation Protocol
   World Health Organization

4. Coordination
   George W. Bush Institute
   World Health Organization

Bill and Melinda Gates Foundation Grant
Improving Data for Decision-Making in Cervical Cancer Programmes (Jan 2014-Dec 2016)
The Field Guide includes:

- Description of the approach
- Tool and Checklists
  - Checklists outlining the roles and responsibilities for each Phase
  - Quick Reference Guides: Tool Field Definitions, and Steps in the Process
  - Survey Tool for all assessment Domains (includes embedded guides for the methods and timing of data collection, as well as the synthesis of the Core and Expanded Assessment Outputs)
    - Country Landscape Domains (1.0-7.0, 9.0)
    - Data and Data Systems Domain (8.0)
- Example of an excel-based Data Synthesis and Analysis Tool
The Population-based Surveys Component
Includes:

- A **core module** including a probe and a set of survey questions related to cervical cancer screening and treatment.
- An **expanded module** that includes the core probe and questions, and an additional 2 probes and 14 survey questions;
- **Instructions** for administering all probes and questions;
- Recommendations on the inclusion of **HPV testing in population-based surveys**;
- A discussion of **methodological considerations** for including cervical cancer questions in existing population-based surveys; and,
- **Example table shells** to use in analysis.
## CORE MODULE

<table>
<thead>
<tr>
<th>Subject Area</th>
<th>Indicators</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Screening</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening Prevalence</td>
<td><strong>C1</strong>: Percentage of women who have been screened for cervical cancer</td>
<td><strong>C1</strong>: Has a healthcare worker ever tested you for cervical cancer?</td>
</tr>
<tr>
<td>Screening Interval</td>
<td><strong>C2</strong>: Median number of years between first and last screenings / Percentage of screened women who were screened within the recommended time frame</td>
<td><strong>C2</strong>: When was your last (most recent) test for cervical cancer?</td>
</tr>
<tr>
<td><strong>Result</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening Result</td>
<td><strong>C3</strong>: Percentage of screened women who received a test result from their most recent screening / Percentage of women that received a specific result</td>
<td><strong>C3</strong>: What was the result of your last test for cervical cancer?</td>
</tr>
<tr>
<td><strong>Follow-up and Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up after Abnormal/Positive/Unclear Result</td>
<td><strong>C4</strong>: Percentage of women with an abnormal result who received follow-up or treatment</td>
<td><strong>C4</strong>: Did you have any follow-up visits or receive any treatment to your cervix because of your test result?</td>
</tr>
</tbody>
</table>
In addition to measuring screening prevalence, screening interval, and follow up and treatment, the expanded cervical cancer screening module also measures:

- Awareness of cervical cancer and cervical cancer screening;
- Age at first screening;
- Screening and treatment location;
- Barriers and facilitators to screening, follow up and treatment;
- Awareness of Human Papillomavirus (HPV) vaccine; and
- HPV vaccination prevalence.
The Patient and Programme Monitoring component provides countries with the following essential resources for M&E:

- Roles & Responsibilities for M&E;
- Indicators;
- Sample Client Screening Form and Data Elements Table;
- Sample Register and Data Elements Table;
- Sample Monthly Summary Form;
- Sample Annual Summary Form;
- DHIS 2 Module;
- Data Visualization Graph and Table Tools; and,
- Data Quality and Training Tools.
### SCREENING RATE AND ASSOCIATED INDICATORS

<table>
<thead>
<tr>
<th>INDICATOR</th>
<th>WHAT IT MEASURES</th>
<th>LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>G1.0 Screening Rate</strong></td>
<td>Percentage of women aged 30-49 years screened for the first time in a 12-month period</td>
<td>☑</td>
</tr>
<tr>
<td><strong>C1.0 Percent Screened</strong></td>
<td>Percentage of women [within the target age range] screened [for the first time] in a given time period</td>
<td>☑</td>
</tr>
<tr>
<td><strong>OPT1.1 Screened Within Target Age Range</strong></td>
<td>Proportion of total women screened for the first time who were within the target age range</td>
<td>☑</td>
</tr>
<tr>
<td><strong>OPT1.2 Progress Toward Target Screening Rate</strong></td>
<td>Percentage of screening target reached in the last [year, quarter, month]</td>
<td>☑</td>
</tr>
</tbody>
</table>
The Facility-Based Surveys component includes:
- Service Availability Tool and Instructions for Use;
- Facility Readiness Assessment Planning Worksheet, Tool, and Instructions for Use;
- Supportive Supervision Planning Worksheet, Tool, and Instructions for Use; and,
- Suggestions for Electronic Survey Administration.

**Service Availability Tool:** create a map of facilities and mobile clinics in to assess the equitable distribution of services with the ultimate aim of improving access.

**Facility Readiness Assessment Tool:** ensure that the facility or mobile clinic has the necessary resources (e.g. staffing, infrastructure, equipment, and supplies) to provide quality services.

**Supportive Supervision Tool:** assess various aspects of quality assurance: health provider skills related to cervical cancer screening and treatment, quality of data collection and use, quality of care, and client or community perception of quality of care at the facility.
<table>
<thead>
<tr>
<th>#</th>
<th>Facility Readiness Category</th>
<th>Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Services</td>
<td>Facility is providing the services it is designated to provide.</td>
</tr>
<tr>
<td>2</td>
<td>Service Utilization</td>
<td>In a facility where services are currently being provided, screening and treatment targets are met.</td>
</tr>
<tr>
<td>3</td>
<td>Staffing</td>
<td>Sufficient numbers of trained providers are currently providing services to meet need.</td>
</tr>
<tr>
<td>4</td>
<td>Potential Staffing (if applicable)</td>
<td>Sufficient number of providers are available who meet selection criteria to be trained in desired skill and are available to provide services once trained.</td>
</tr>
<tr>
<td>5</td>
<td>Infrastructure</td>
<td>Items are present and functional (include over the past 3 months).</td>
</tr>
<tr>
<td>6</td>
<td>Procurement and Supply Chain</td>
<td>A functional procurement and supply chain system is in place, as defined by the 4 items below.</td>
</tr>
<tr>
<td>7</td>
<td>Equipment and Supplies</td>
<td>Items are of sufficient quantity, continuously available, and functional (include over the past 3 months).</td>
</tr>
<tr>
<td>8</td>
<td>Infection Prevention</td>
<td>Items are continuously available and functional (include over the past 3 months).</td>
</tr>
<tr>
<td>9</td>
<td>Medicines and Laboratory</td>
<td>Items are continuously available and accessible.</td>
</tr>
<tr>
<td>10</td>
<td>Data Management</td>
<td>Items (materials and processes) are continuously available and functional (include over the past 3 months).</td>
</tr>
<tr>
<td>11</td>
<td>Referral Mechanisms</td>
<td>Referral mechanisms are clearly defined and functional.</td>
</tr>
<tr>
<td>12</td>
<td>Policies and Guidelines</td>
<td>Relevant and current national guidelines and policies are displayed or readily available, and well understood.</td>
</tr>
<tr>
<td>13</td>
<td>Community Sensitization/Mobilization</td>
<td>In the last 3 months, the following activities have been continuously conducted and material present.</td>
</tr>
</tbody>
</table>
The C4P-ST component provides the guiding information needed to inform a multidisciplinary costing team through navigation of the use of the tool including:

- Guiding information on **how to adapt the tool** based on country-specific, cervical cancer screening and treatment service priorities.
- **An orientation to the tool** including information on software requirements and tool layout.
- A section outlining the **cost categories and the service outputs** the tool can provide. Recommendations on how to **build an in-country planning and costing team** and conduct planning team meetings.
- **Instructions for using the tool** from data collection to decision making.
- **Intersections** between the C4P-ST and other IDCCP Toolkit components.
- The Appendices include an **illustrative table of data requirements** that can guide data collection; and **additional guiding information on cost categories**.
PROJECT TIMELINE

April – December, 2015
Toolkit development
- Baseline situational assessments completed
- Development of tools and guiding information
- Global consultation
- Cognitive and Field testing

January – June, 2016
- WHO and CDC review process
- Toolkit refinement
- Partner workshop

July – December, 2016
- Robust Awareness Generation and Active Dissemination
  - Stop Cervical Cancer in Africa (SCCA)
  - Asia Pacific Economic Cooperation (APEC)
  - World Cancer Congress (WCC)

- Workshops and Capacity Building to support Uptake and Adaptation
Caribbean Cancer Registry Hub

One of the six hubs under the Global Initiative for Cancer Registries

- **Goal: Improve the collection of high-quality cancer registry data in the Caribbean**
  - Directed support (Site visits and consultancy)
  - Training (e.g. Delivery of basic/advanced, technical courses)
  - Research networks (Foster relationships between disciplines e.g. cancer registrars and epidemiologists, epidemiologists and economists)
  - Cancer control (Support cancer control interventions, cancer control forums)
Hub located at CARPHA headquarters in Port-of-Spain, Trinidad and Tobago

PI: Glennis Andall-Brereton

Program Coordinator: Sarah Quesnal-Crooks
Caribbean Hub

• **Key activities:**
  - Build and sustain capacity for cancer registration. Provide training and technical support.
  - Promote networking among cancer registries.
  - Foster collaborative research within the region.

• **Goals over the next decade:**
  - Establishment of a data repository.
  - Conduct in-depth analyses of data for the region.
  - Facilitate the development of regional networks.
Timeline of Caribbean Hub Major Activities

- April, 2014: Cancer Registry Workshop
- Jan, 2015: Site Visits to CARPHA to initiate Registry Hub Planning
- June, 2015: Presentation of Registry Hub to Chief Medical Officers
- June, 2016: Hub Basic Training Workshop
- April, 2016: Hub visits T&T Barbados
- August, 2016: Hub visits Bahamas Jamaica
- Nov, 2016: CANREG5 Workshop
Recent Activities

Country site visits:
Trinidad and Tobago and Barbados: April, 2016
Jamaica and Bahamas: August, 2016

Objectives:
• To provide guidance, consultancy and technical assistance
• To formulate recommendations after the visit and assess feasibility of Collaborative Research Agreement for improvement of cancer registration.
Recent Activities

Basic Training workshop (June, 2016)
Turks and Caicos in conjunction with CARPHA conference
Approximately 18 attendees from 14 Caribbean countries
Objectives:
• Understand the cancer burden in the Caribbean region and around the world.
• Learn about the Global Initiative for Cancer Registration (GICR) & specifically the GICR Caribbean Hub.
• Learn about status of cancer registration in Caribbean countries and discuss models for collection of cancer data from countries, including collaborative or sub-regional approaches for countries with smaller populations (</=100,00).
• Learn fundamentals of a cancer registry and how data can be use for cancer control planning.
Recent Activities

CANREG 5 workshop (November, 2016)

Location: National Cancer Institute, Shady Grove Campus

Will host 4 – 5 Caribbean countries for technical assistance in use of CANREG 5 software

Objectives:

• Learn basic background of cancer epidemiology and cancer registration, including basic terminology, structure, and function of a cancer registry
• Perform in-class training on using CANREG5 software for data recording and tabulations
• Be provided with an overview of evaluation and assessment techniques for cancer registration data quality
• Develop a network among cancer registrars to provide support for each other for peer mentoring in their future work
Upcoming MMWR report December 2016
Data Sources

• Most recent, available 5 years of mortality data for each country from 2003-2013

• Population data from the census were used
  ▪ When unavailable for all study period, the most recent year of available data were used to populate subsequent years

• U.S., PR, and USVI mortality and population data were obtained from the National Center on Health Statistics
Summary of Findings

- Cancer was a leading cause of death
- Prostate and breast cancers were the leading causes of cancer-related deaths
- Mortality rates due to cervical and prostate cancers were 2 to 9 times and 2 to 8 time higher in the Caribbean compared to the US, respectively
- Mortality rates due to lung and bronchus cancers were lower for both males and females in the Caribbean region
Overall Cancer-Related Mortality for Females

Mortality Rates, females, age-adjusted, per 100,000.
All cancer sites combined:

- High (93.2 - 123.3)
- Middle (70.2 - 93.2)
- Low (32.1 - 70.2)
- Not reported, too few deaths for stability

US Mortality Rates: 87.2
Overall Cancer-Related Mortality for Males

Data source: CARPHA, NCHS
Map production: IARC
World Health Organization © WHO 2011. All rights reserved

Mortality Rates, males, age-adjusted, per 100,000
All cancer sites combined.

- High (125.1 - 167.6)
- Middle (99 - 125.1)
- Low (50.8 - 99)
- Not reported, too few deaths for stability

US Mortality Rates: 118.4
THANK YOU
MSARAIYA@CDC.GOV