How is the U.S. doing in controlling cervical cancer? And more importantly, what information systems are they using? --And the Toolkit for Cervical Cancer Screening

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PAHO August 1-2, 2019 –Washington DC

WHO's call for global cervical cancer elimination

WHO Targets to Eliminate Cervical Cancer

Reduce cervical cancer incidence to <4 / 100,000 woman

Targets:

- 70% of countries to introduce HPV vaccination into national vaccination schedule by **2020**
- 90% of girls aged 15y vaccinated (2 doses) by **2030** in countries
- 70% women screened with HPV test at 35 & 45 years and managed by **2030**
- 30% reduction in cervical cancer mortality by **2030**

Timeline to Achieve Cervical Cancer Elimination Goal

Starting cervical cancer incidence rate	Year Goal is Reached
High (>20/100,00)	2080
Medium (10-20/100,000)	2060
Low (<10/100,000)	2050

https://www.who.int/reproductivehealth/call-to-action-elimination-cervical-cancer/en/

WHO's call for global cervical cancer elimination (most recent draft May 30)

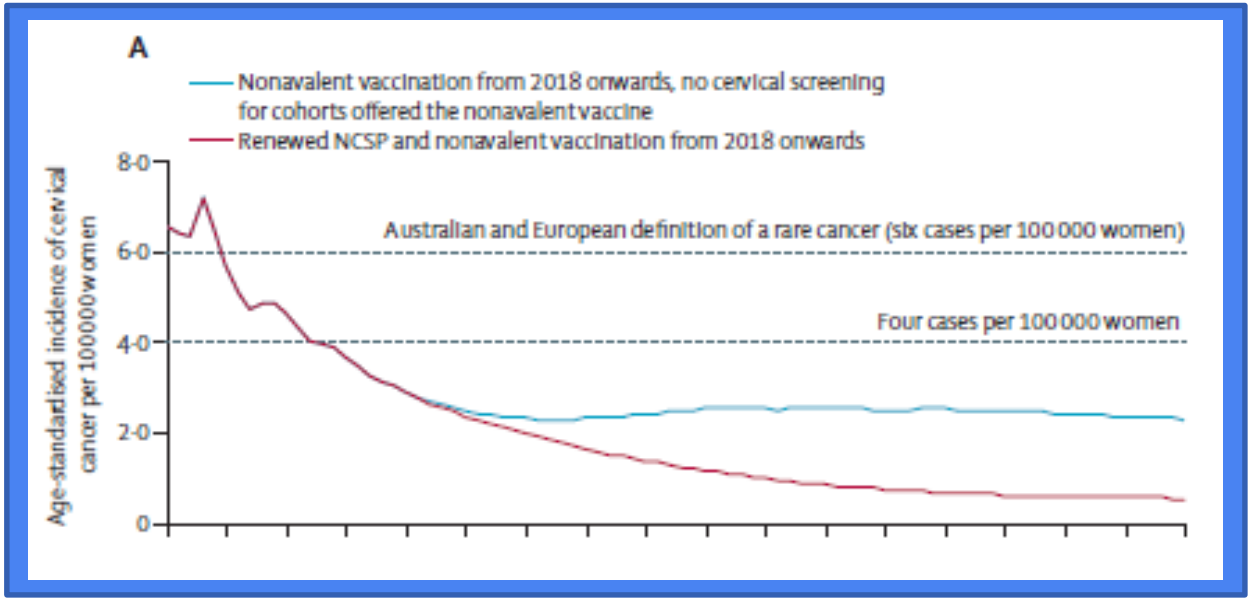
- To achieve elimination goal of elimination by 2090, following need to be met by 2030
- **90%** of girls fully vaccinated with the HPV vaccine by 15 years of age;
- **70%** of women are screened with a high-precision test at 35 and 45 years of age; and
- **90%** of women identified with cervical disease receive timely and appropriate treatment and care

How does WHO define cervical cancer elimination?

- Rare cancer threshold
  - 6 cases per 100,000 women per year
  - used in Europe and Australia

- Lower threshold
  - 4 cases per 100,000 women per year

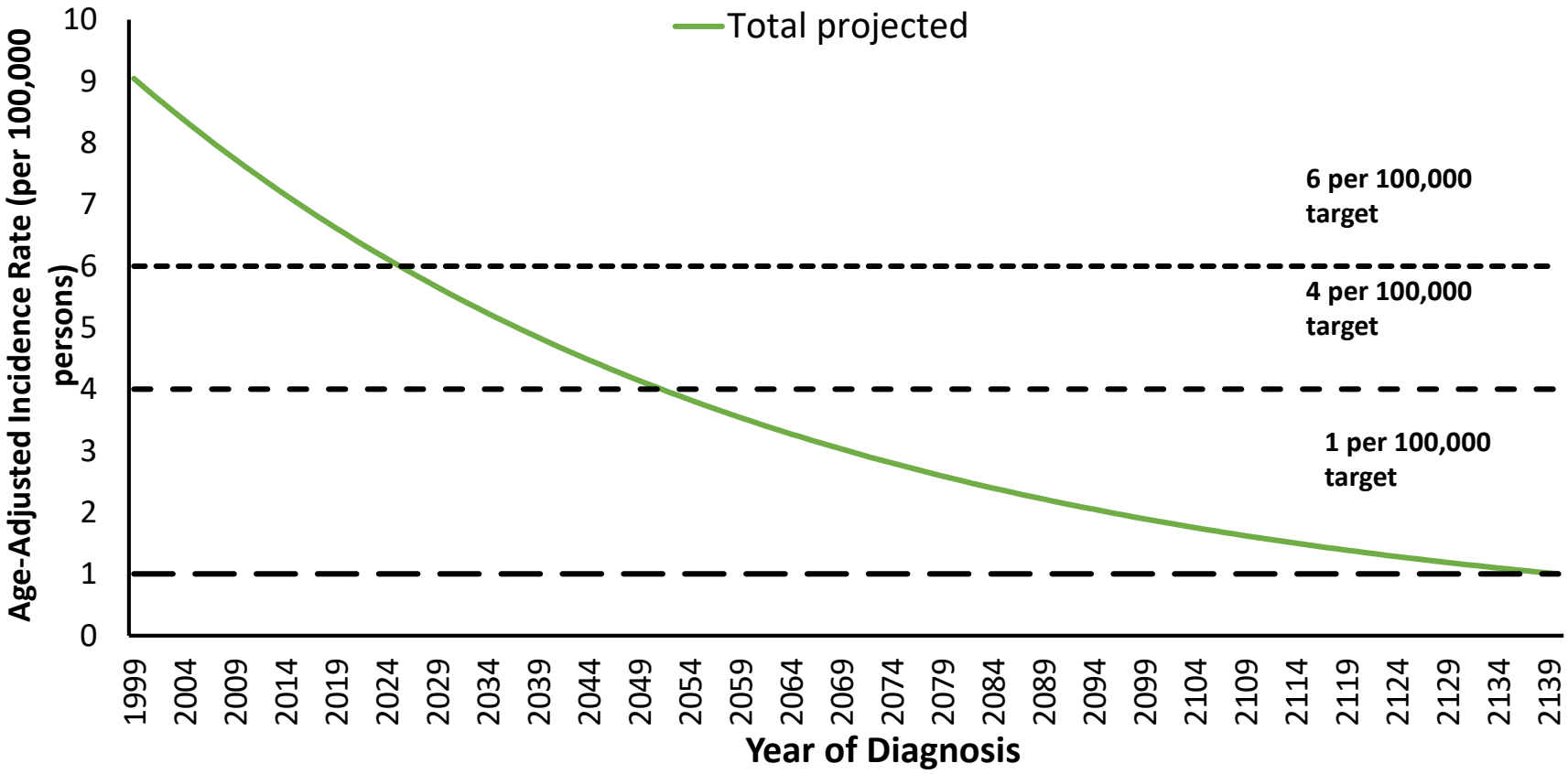
Australia's cervical cancer elimination model



- Using the threshold of 4 per 100,000 women, Australia could eliminate cervical cancer within the next 20 years

Hall MT, et al. The projected timeframe until cervical cancer elimination in Australia: a modelling study. Lancet Public Health. 2019;4(1):e19-e27.

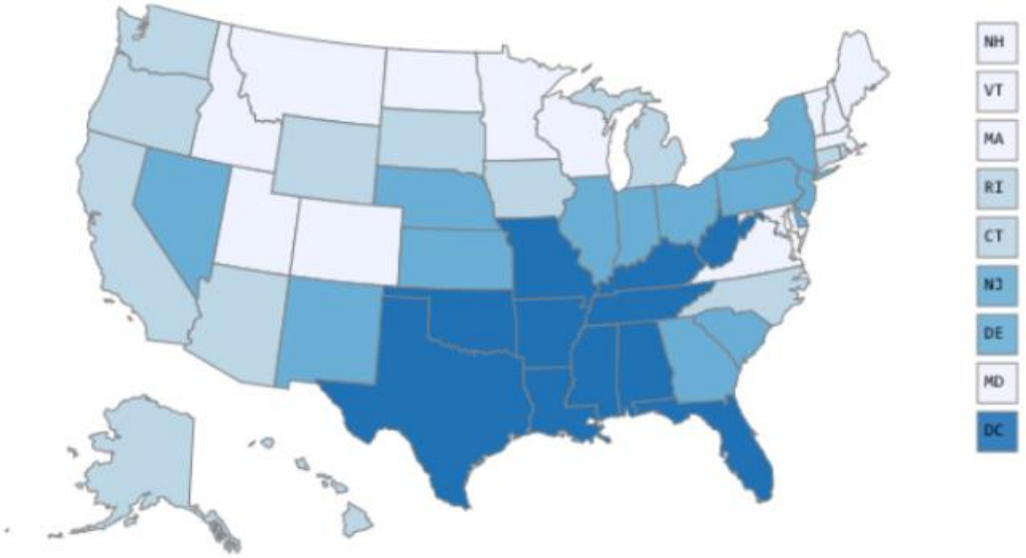
Simple Projection if rates from 1999-2015 continued in US Cervical Cancer



Data Source: Cancer Incidence

- United States Cancer Statistics (USCS) database
- Covers all 50 states, the District of Columbia, and Puerto Rico
- For 1999–2015, registry data that met specific quality standards covered ~98% of the U.S. population

Very few states with incidence rate of 4-6 cases per 100,000, Cervical Cancer, 2011-2015

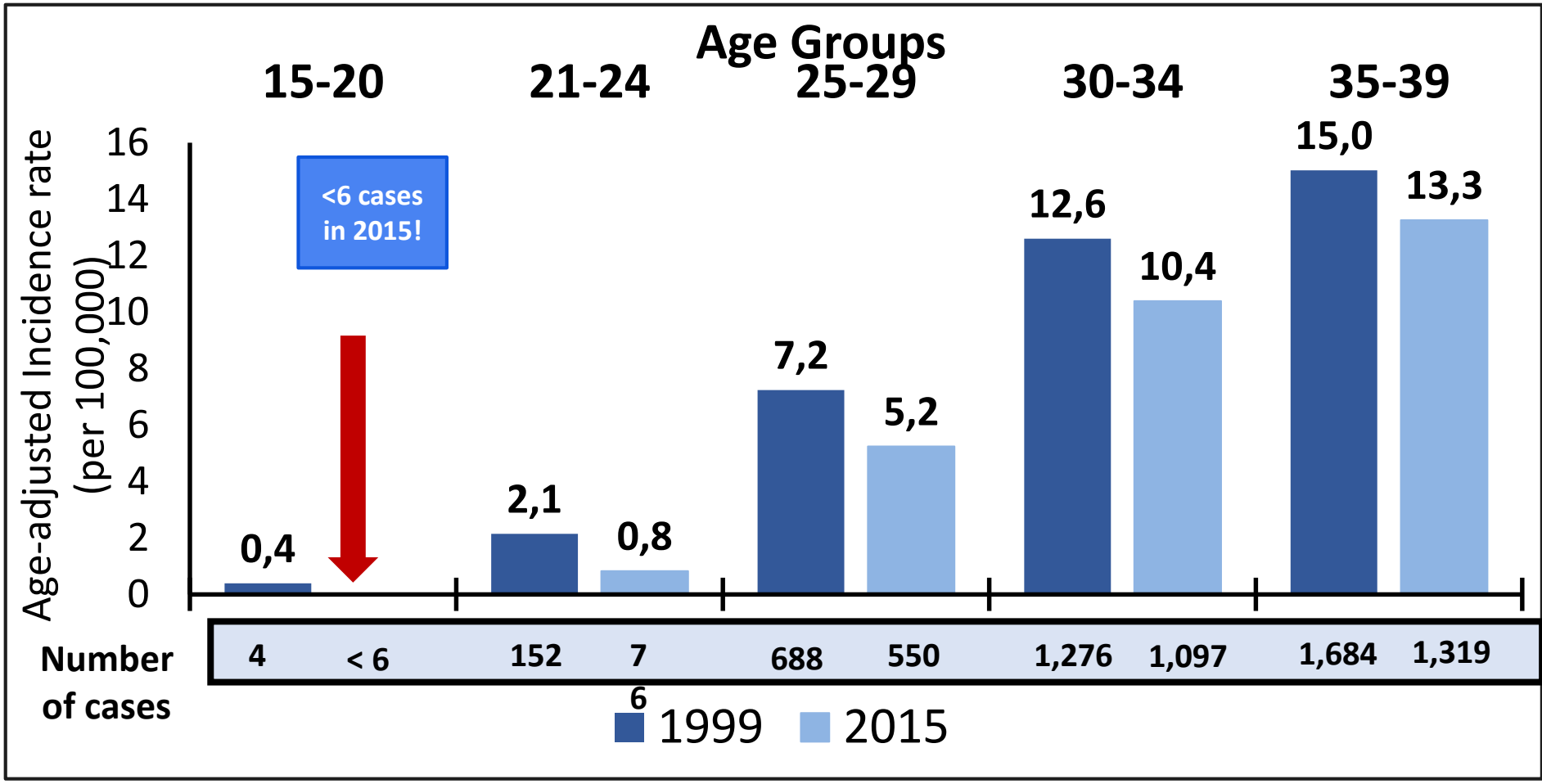


Vermont, New Hampshire, North Dakota and Utah

DC, Arkansas, Missisippi, Texas

https://gis.cdc.gov/Cancer/USCS/DataViz.html

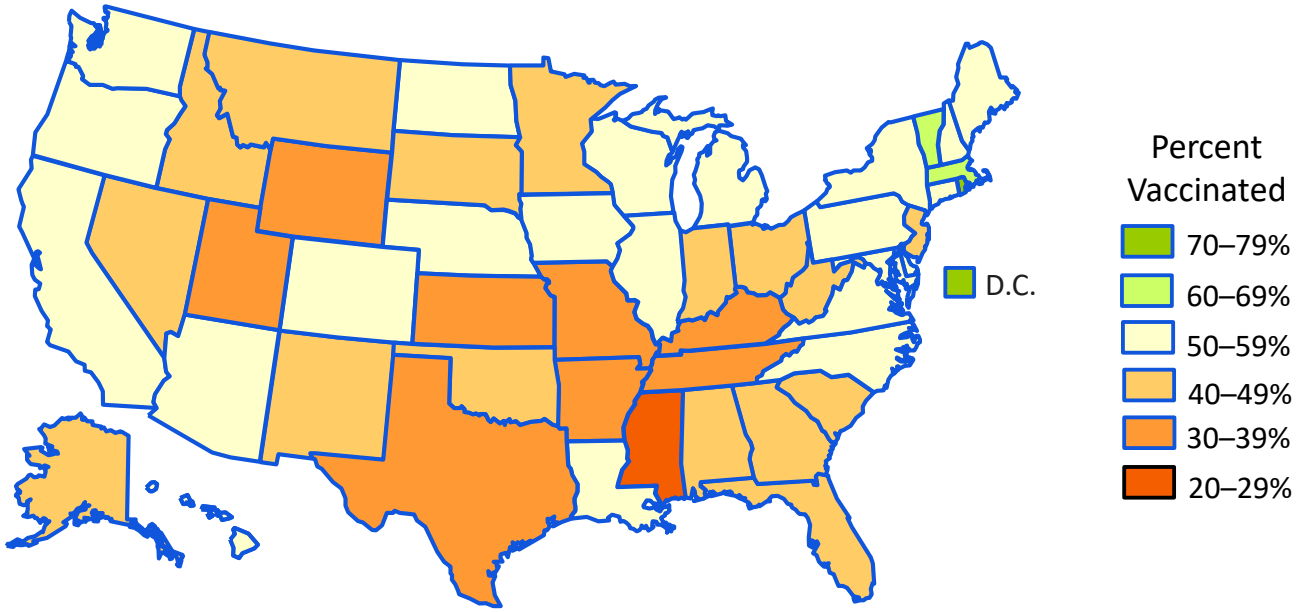
Cervical cancer rates declined from 1999 to 2015, United States



Measure: Up to Date HPV Vaccination, 2017

- Source: National Immunization Survey
- Has generally been validated by medical record data
- Up to Date HPV coverage is 50%

HPV Vaccination Rates Vary Widely Across the U.S.

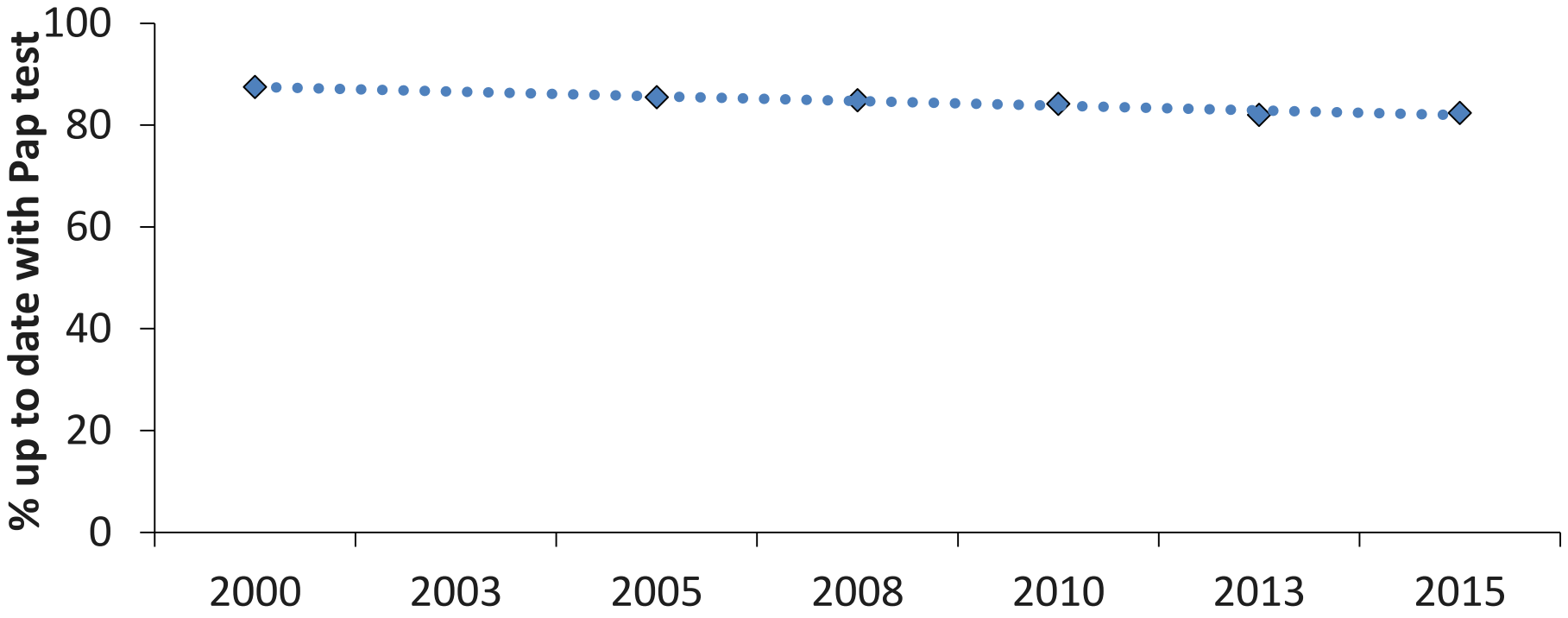


Walker TY, Elam-Evans LD, Yankey D, et al. MMWR 2018;67:909–917

Measure: Up to Date Screening

- No screening registry in the United States
- Healthy People 2020 uses National Health Interview Survey
- States use Behavioral Risk Factor Survey
- PROSPR Survey (of select integrated health delivery systems)—medical record data
- Health care use HEDIS to measure up to date screening-use medical records

Up to Date Cervical Cancer Screening
National Health Interview Survey, 2000-2015



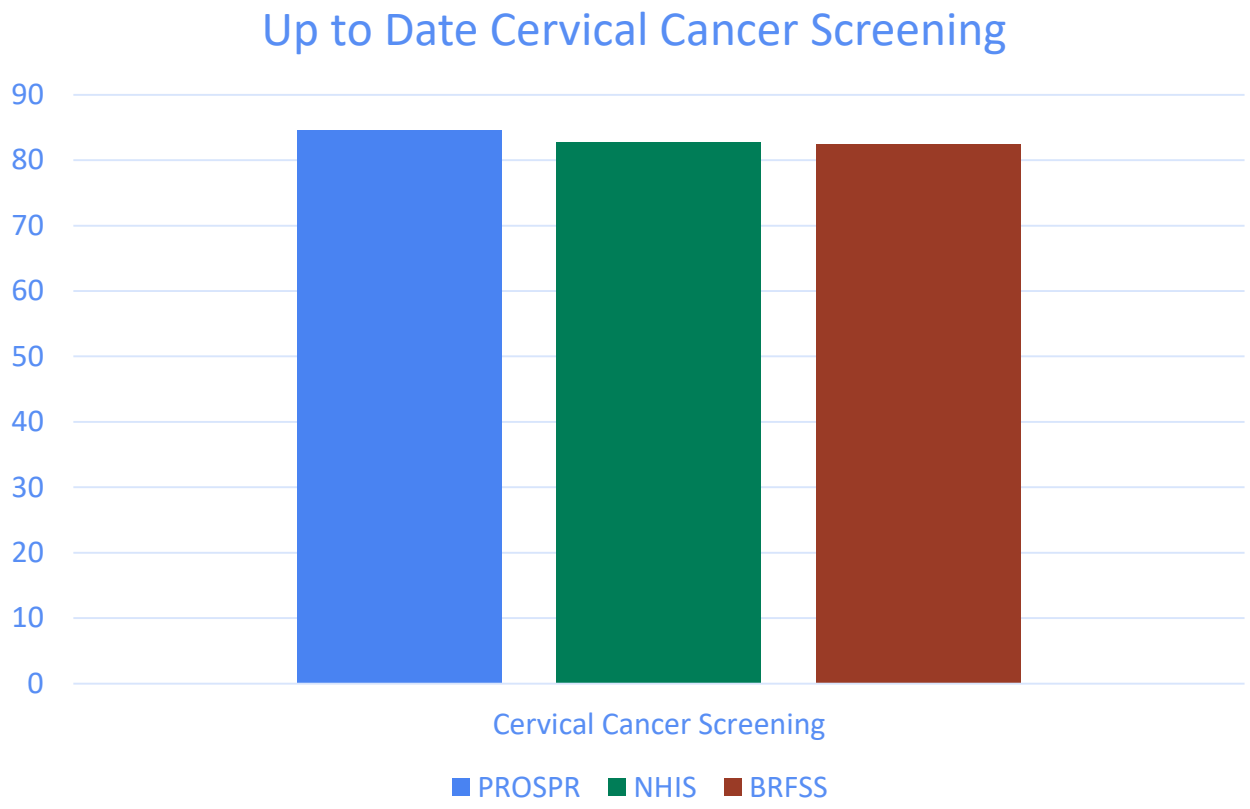
White, et al. Cancer Screening Test Use — United States, 2015. MMWR Morb Mortal Wkly Rep 2017;66:201–206

Up to Date Screening varies by select groups, National Health Interview Survey, 2015

- Lower among specific race/ethnicity
  - Hispanics
  - Asians
  - Native Americans/Alaska Natives
- Foreign-Born
- Lower Educated
- Underinsured/Uninsured

White, et al. Cancer Screening Test Use — United States, 2015. MMWR Morb Mortal Wkly Rep 2017;66:201–206

PROSPR vs National Surveys



Barlow et al, Evaluating screening participation, follow-up and outcomes for breast, cervical and colorectal cancer in the PROSPR consortium, JNCI 2019

HEDIS Measures for Cervical Cancer Screening, 2017

- Commercial HMO: 74.3%
- Commercial PPO: 74.2%
- Medicaid HMO: 59.4%

NCQA website: https://www.ncqa.org/hedis/measures/cervical-cancer-screening/

Quality Indicators for CDC Program Performance

Indicator	Target	PY 2013 Result
Women rarely/never screened for cervical cancer	≥ 20%	34.5%
Cervical diagnosis completed	≥ 90%	93.7%
Cervical diagnosis completed with 90 days	≥ 75%	88.3%
Cervical treatment initiated	≥ 90%	93.3%
Cervical treatment initiated within 60 days (Invasive)	≥ 80%	91.3%
Cervical treatment initiated within 90 days (CIN2/3)	≥ 80%	94.2%

Measure: Follow up and Treatment

- No national screening and followup registry
- CDC National Breast and Cervical Cancer Screening has indicators for followup
- Highly variable based on health care system
- Information on invasive cancer –can be found for nation in Cancer registries –for time to first course of treatment

NCQA website: https://www.ncqa.org/hedis/measures/cervical-cancer-screening/

IMPROVING DATA FOR DECISION-MAKING

A TOOLKIT FOR CERVICAL CANCER PREVENTION AND CONTROL PROGRAMMES

Mona Saraiya MD, MPH –Centers for Disease Control and Prevention
PAHO Cervical Cancer Elimination Meeting, August 1-2, 2019

ACKNOWLEDGEMENTS

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IDENTIFIED NEED

A global absence of standardised tools and guidance, technical expertise, and implementation support for countries that are seeking to collect and use high-quality data to monitor, evaluate, and improve their cervical cancer screening and treatment programs.

Photo: WHO/P Goldschmid

PROJECT OBJECTIVE

To improve and accelerate the availability of data for planning and improving global cervical cancer programmes by gathering information on data systems in select country contexts, and by developing global standards, tools, and guidance.

Photo: WHO/S Bones

TOOLKIT STRUCTURE

How to identify opportunities for strengthening country data and data systems?	SECTION 1: RAPID SITUATIONAL ASSESSMENT OF DATA AND DATA SYSTEMS
How to measure population coverage of cervical cancer screening and secondary prevention?	SECTION 2: POPULATION-BASED SURVEY MODULES
How to routinely monitor patients and programs?	SECTION 3: PATIENT AND PROGRAMME MONITORING
How to survey facilities for service readiness, service availability, service quality?	SECTION 4: FACILITY-BASED SURVEYS
How to estimate costs of cervical cancer screening & treatment programs?	SECTION 5: PREVENTION AND CONTROL COSTING

Rapid situational assessment of data and data systems

01

PURPOSE

The Rapid Situational Assessment of Data and Data Systems supports countries to identify opportunities and challenges associated with implementing data systems for primary and secondary cervical cancer prevention and invasive cervical cancer treatment.

The goal of the data systems assessment is to contribute to the available evidence-base for planning and implementing cervical cancer monitoring and evaluation, surveillance, and information systems through documentation and analysis of country landscape, information systems, programmes, and services. This documentation and subsequent analysis leads to the development of actionable country-level recommendations.

OVERVIEW OF COMPONENTS

The steps and processes presented in the Data Systems Assessment Field Guide should act as a core foundation and can be further adapted and expanded into Standard Operating Procedures (SOPs), data collection tools, job aids and other practical materials for assessment implementation.

The Field Guide includes:

- Description of assessment approach
- Field Guide for planning and conducting the Data Systems Assessment
- Assessment Tool
  - Checklists outlining the roles and responsibilities for each phase of the assessment
  - Quick Reference Guides: Assessment Tool Field Definitions, and Steps in the Assessment Process
  - Data Systems Assessment Survey Tool for all assessment Domains (includes embedded guides for the methods and timing of data collection, as well as the synthesis of outputs)
- Example of an excel-based Assessment Data Synthesis and Analysis Tool

Population-based survey modules

02

PURPOSE

Population-based surveys can be used to assess cervical cancer screening coverage, and to identify barriers to accessing screening and precancerous treatment services. They were developed to provide country stakeholders with standardized cervical cancer screening and treatment questions that can be incorporated into existing population-based surveys.

The use of standardized questions will help ensure that collected data are useful for programme planning and evaluation, and are comparable over time and across countries.

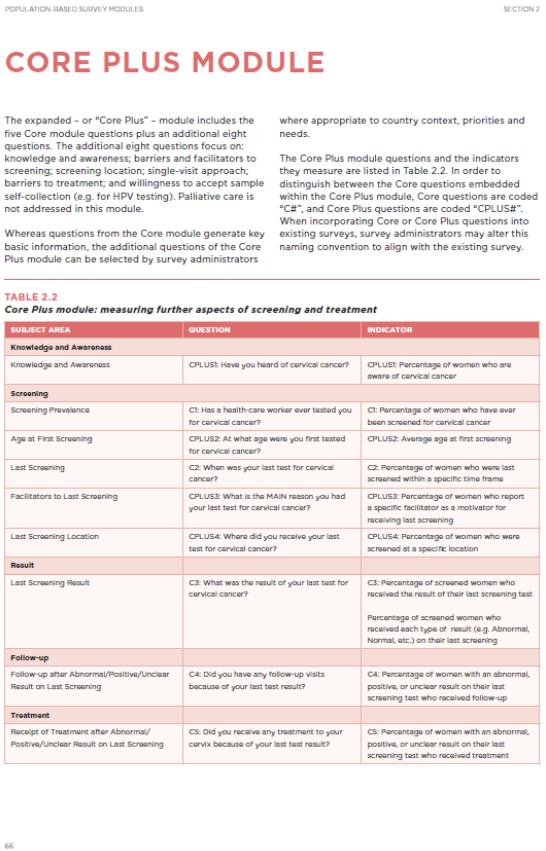
This component assists low-and middle-income countries in monitoring key indicators and measures of cervical cancer screening and treatment including:

- Screening prevalence; Screening interval; Follow-up and treatment of precancer; Single Visit Approach; HPV vaccination; Knowledge and awareness; Facilitators to screening; and, Barriers to screening and treatment.

OVERVIEW OF COMPONENTS

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 of precancerous lesions
- An expanded module that includes the core probe and questions as well as additional probes and survey questions
- Instructions for administering all probes and questions
- A cautionary statement on the inclusion of HPV DNA testing in population-based surveys
- A discussion of methodological considerations for including PSCC questions in existing population-based surveys
- Example table shells for use in analysis



POPULATION-BASED SURVEY MODULES SECTION 2

CORE PLUS MODULE

The expanded – or "Core Plus" – module includes the five Core module questions plus an additional eight questions. The additional eight questions focus on: knowledge and awareness; barriers and facilitators to screening; screening location; single-visit approach; barriers to treatment; and willingness to accept sample self-collection (e.g. for HPV testing). Palliative care is not addressed in this module.

Whereas questions from the Core module generate key basic information, the additional questions of the Core Plus module can be selected by survey administrators where appropriate to country context, priorities and needs.

The Core Plus module questions and the indicators they measure are listed in Table 2.2. In order to distinguish between the Core questions embedded within the Core Plus module, Core questions are coded "C#", and Core Plus questions are coded "CPLUS#". When incorporating Core or Core Plus questions into existing surveys, survey administrators may alter this naming convention to align with the existing survey.

TABLE 2.2

Core Plus module: measuring further aspects of screening and treatment

SUBJECT AREA	QUESTION	INDICATOR
Knowledge and Awareness		
Knowledge and Awareness	CPLUS1: Have you heard of cervical cancer?	CPLUS1: Percentage of women who are aware of cervical cancer
Screening		
Screening Prevalence	C1: Has a health-care worker ever tested you for cervical cancer?	C1: Percentage of women who have ever been screened for cervical cancer
Age at First Screening	CPLUS2: At what age were you first tested for cervical cancer?	CPLUS2: Average age at first screening
Last Screening	C2: When was your last test for cervical cancer?	C2: Percentage of women who were last screened within a specific time frame
Facilitators to Last Screening	CPLUS3: What is the MAIN reason you had your last test for cervical cancer?	CPLUS3: Percentage of women who report a specific facilitator as a motivator for receiving last screening
Last Screening Location	CPLUS4: Where did you receive your last test for cervical cancer?	CPLUS4: Percentage of women who were screened at a specific location
Result		
Last Screening Result	C3: What was the result of your last test for cervical cancer?	C3: Percentage of screened women who received the result of their last screening test Percentage of screened women who received each type of result (e.g. Abnormal, Normal, etc.) on their last screening
Follow-up		
Follow-up after Abnormal/Positive/Unclear Result on Last Screening	C4: Did you have any follow-up visits because of your last test result?	C4: Percentage of women with an abnormal, positive, or unclear result on their last screening test who received follow-up
Treatment		
Receipt of Treatment after Abnormal/ Positive/Unclear Result on Last Screening	C5: Did you receive any treatment to your cervix because of your last test result?	C5: Percentage of women with an abnormal, positive, or unclear result on their last screening test who received treatment

66

Patient and programme monitoring

+ Purpose

+ Overview of components

03

PURPOSE

The Patient and Programme Monitoring component outlines a process for data collection, aggregation, analysis, and reporting for cervical cancer secondary prevention (screening and precancerous lesion treatment) programmes. It includes guiding information on indicator development, improvement of programme responsiveness and effectiveness, as well as sample data collection and management tools.

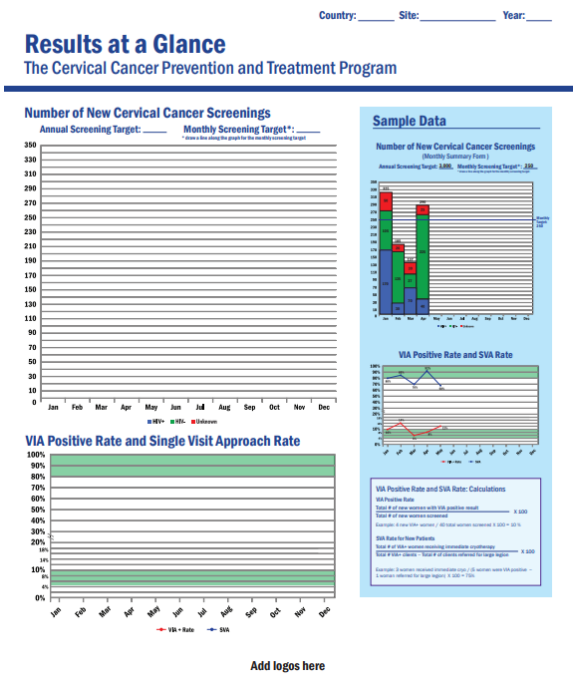
This component provides resources to assist health care providers, facility managers, subnational and national Ministry of Health staff and their partners to collect, systematically analyze and use data to:

- Better plan, target, tailor, and scale interventions;
- Assess whether programmes are being implemented with quality;
- Respond effectively when they are not implemented as planned; and,
- Report on standardized global indicators.

OVERVIEW OF COMPONENTS

The Patient and Programme Monitoring component provides countries with the following essential resources:

- Roles & Responsibilities for M&E;
- A set of Core and Optional Indicators for Global, National, Sub-national, and Facility levels;
- Client Screening Form Data Element Checklist and Sample Form;
- Register Data Element Checklist and Sample Register;
- Sample Monthly Summary Form for reporting;
- Sample Annual Summary Form for reporting;
- Data Visualization Graph and Table Tools; and
- Data Quality and Training Tools.



INDICATORS

- These indicators are focused on data derived from the provision of screening and treatment services, and demonstrate how a programme is progressing towards expected outputs, outcomes, and results.

- The purpose of the indicators table and accompanying guiding information is to help countries select appropriate routine service delivery and programme indicators in order to generate meaningful, actionable data for decision-making.

- Data required to calculate the indicators should be collected and collated on a monthly, quarterly, or annual basis as appropriate, aggregated in a timely manner, and analysed to inform programme implementation.

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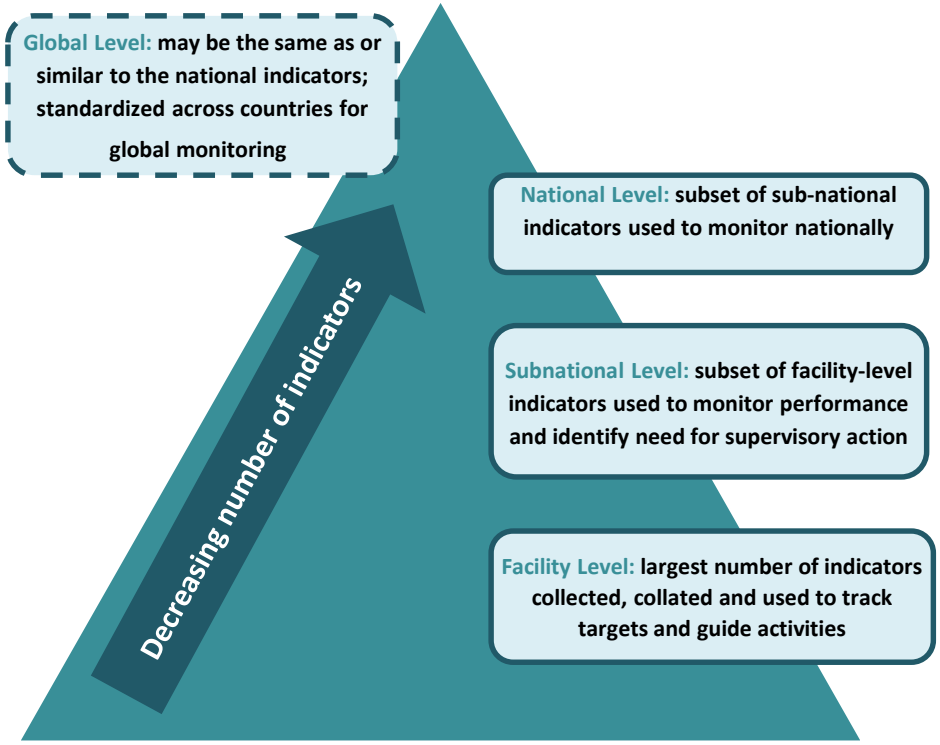
INDICATORS: DATA FLOW



INDICATORS: NATIONAL, SUB-NATIONAL, AND FACILITY-LEVEL

NATIONAL LEVEL INDICATORS

- Provide countries with a focused and comprehensive overview that informs programme tracking and management.

SUB-NATIONAL LEVEL INDICATORS

- Include additional programme data (e.g. training, facility-based surveillance, etc.) and routine service delivery data.

FACILITY LEVEL INDICATORS

- Data are collected in paper-based client screening form and register/logbook.
- Facilities also complete monthly summary forms that summarize all individual client data, and track facility performance.
- Aggregate data from the monthly summary forms inform the sub-national, national, and global level indicators calculated by the electronic HMIS system.

INDICATORS: GLOBAL, CORE, AND OPTIONAL

Indicators in table included in the next slide are organized into 3 categories: **Global**, **Core**, and **Optional**.

- **Global indicators** are the three globally standardized performance indicators recommended by WHO as fundamental to monitoring a cervical cancer prevention programme.

- **Core indicators** allow countries with limited resources to monitor a small set of 'must-have' basic indicators. The suggested **Core indicators** align with the WHO-recommended performance indicators, while allowing for flexibility to adapt the indicators to fit the country programme context.

- **Optional indicators** can be incorporated into the M&E system based on the maturity of, and resources available for the country programme.

INDICATORS: GLOBAL, CORE, AND OPTIONAL

INDICATOR G = Global; C = Core; OPT = Optional	WHAT IT MEASURES	LEVEL			
		G	N	S	F
G1.0 Screening Rate	**Percentage of women aged 30-49 years screened for the first time in a 12-month period**	√	√	√	√
C1.0 Percent Screened	**Percentage of women [within the target age range] screened [for the first time] in a given time period**		√	√	√
OPT1.1 Screened Within Target Age Range	Proportion of total women screened for the first time who were within the target age range			√	√
OPT1.2 Progress Toward Target Screening Rate	Percentage of screening target reached in the last [year, quarter, month]		√	√	√
G2.0 Screening Test Positivity Rate	**Percentage of screen-positive women aged 30-49 years with a positive result in a 12-month period**	√	√	√	√

INDICATORS: GLOBAL, CORE, AND OPTIONAL

INDICATOR G = Global; C = Core; OPT = Optional	WHAT IT MEASURES	LEVEL			
		G	N	S	F
C2.0 Screening Test Percent Positive	**Percentage of [first time] screened women [within the target age range] who received a positive screening result in a given time period**		√	√	√
C2.1 Suspected Cancer Cases	**Percentage of [first time] screened women [within the target age range] with suspected cervical cancer**		√	√	√
G3.0 and C3.0 Treatment Rate	**Percentage of screen-positive women who have received treatment in a given time period**	√	√		
OPT3.1 Precancerous Lesion Treatment	Percentage of screen-positive women with lesions eligible for cryotherapy or LEEP who received that treatment		√	√	
OPT3.2 Treatment with Cryotherapy	Percentage of screen-positive women with lesions eligible for cryotherapy who received cryotherapy			√	√

INDICATORS: GLOBAL, CORE, AND OPTIONAL

INDICATOR G = Global; C = Core; OPT = Optional	WHAT IT MEASURES	LEVEL			
		G	N	S	F
OPT3.2.1 Single Visit Approach Rate	Percentage of VIA-positive women with lesions eligible for cryotherapy treated during the same visit			√	√
OPT3.2.2 Postponed Cryotherapy	Percentage of VIA-positive women with lesions eligible for cryotherapy who postponed cryotherapy				√
OPT 3.2.3 Cryotherapy After Postponement	Percentage of VIA-positive women with lesions eligible for cryotherapy who received cryotherapy after postponing				√
OPT3.2.4 Did Not Return for Cryotherapy	Percentage of VIA-positive women with lesions eligible for cryotherapy who did not return for cryotherapy after postponing				√
OPT3.3 Treatment for Large Lesions	Percentage of screen-positive women referred for large lesions who received LEEP			√	√

INDICATORS: GLOBAL, CORE, AND OPTIONAL

INDICATOR G = Global; C = Core; OPT = Optional	WHAT IT MEASURES	LEVEL			
		G	N	S	F
OPT3.3.1 Large Lesion Referral	Percentage of screen-positive women referred for large lesions (lesions not eligible for cryotherapy)			√	√
OPT3.3.2 Large Lesion Treatment Eligibility	Percentage of screen-positive women referred for large lesions who were eligible for LEEP			√	√
OPT3.4 Suspected Cancer Treatment/Follow-up	Percentage of women with suspected invasive cancer who completed appropriate treatment or follow-up		√		
OPT3.4.1 Suspected Cancer Referral	Percentage of screen-positive women who were referred for suspected cancer			√	√
OPT3.4.2 Suspected Cancer Referral Compliance	Percentage of screen-positive women referred for suspected cancer who attended the referral visit			√	√

INDICATORS: GLOBAL, CORE, AND OPTIONAL

INDICATOR G = Global; C = Core; OPT = Optional	WHAT IT MEASURES	LEVEL			
		G	N	S	F
OPT3.5 Confirmed Cancer	Percentage of screen-positive women referred for suspected cancer who were diagnosed with cancer		√		
OPT4.0 Post-treatment Complication	Percentage of women receiving cryotherapy or LEEP who returned with a post-treatment complication		√	√	√
OPT5.0 Rescreening Within Target Interval	Percentage of women who were rescreened within the recommended screening interval			√	√
OPT5.1 Precancerous Lesion Post-treatment Follow-up	Percentage of women treated for precancerous lesions who return for a 1 year post-treatment follow-up screening test			√	√
OPT5.2 Precancerous Lesion Cure Rate	Percentage of women who received a negative screening result at their 1 year post-treatment follow-up			√	√

INDICATORS: GLOBAL, CORE, AND OPTIONAL

INDICATOR G = Global; C = Core; OPT = Optional	WHAT IT MEASURES	LEVEL			
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OPT5.0 Rescreening Within Target Interval	Percentage of women who were rescreened within the recommended screening interval			√	√
OPT5.1 Precancerous Lesion Post-treatment Follow-up	Percentage of women treated for precancerous lesions who return for a 1 year post-treatment follow-up screening test			√	√
OPT5.2 Precancerous Lesion Cure Rate	Percentage of women who received a negative screening result at their 1 year post-treatment follow-up			√	√

Facility-based surveys

04

PURPOSE

The Facility-based Surveys component provides Ministry of Health decision-makers, implementing partners, facility administrators, and service providers with the tools to gather and evaluate accurate, up-to-date information on the availability of cervical cancer secondary prevention services, the readiness and capacity to deliver services, and the quality of the services being delivered.

Photo: Christine McNab

OVERVIEW OF COMPONENTS

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, Instructions for Use
- Suggestions for Electronic Survey Administration

The Facility-based Surveys component is structured to be user-friendly and easy to understand, with detailed user instructions for each tool. The structure of this component allows countries to use each tool individually, or to use the package of three tools as part of a comprehensive approach to monitoring cervical cancer screening and precancerous lesion treatment service availability, capacity, and quality.

Prevention and control costing-analysis and planning module for screening and treatment

05

PURPOSE

Policymakers and programme managers need information on the projected costs of introducing cervical cancer interventions in order to make decisions on the 'when' and the 'where' of service introduction and scale-up. Through a facilitated process, the MS Excel-based tool allows health programme planners and managers to estimate, synthesize and analyze programme and service costs including:

- Early detection of cervical cancer;
- Diagnosis;
- Treatment of precancerous lesions and invasive cancer;
- Palliative care for advanced disease;
- Community outreach and sensitization;
- Programme planning, monitoring and evaluation; and,
- Supportive supervision.

OVERVIEW OF COMPONENTS

Photo: WHO/S Bones

Trained facilitators will use this tool and the accompanying user manual to assist programme planners, managers and implementers to:

- Estimate service costs and service coverage based on country-specific data and needs;
- Estimate financial and economic costs, and start up and recurrent costs of cervical cancer programmes;
- Estimate service coverage rates based on cost, distribution, population need and predicted scale-up; and,
- Explore cost/service access trade-offs based on different models of public service delivery.

Outcome Evaluation Component

+ To longitudinally examine cohort

+ IARC was partner

+ Must request this individually to WHO

06

The toolkit was largely built around secondary prevention

- Toolkit doesn't have tools for audit
- It can be linked to more f/u data or allow more longitudinal f/u

- A successful followup register would have to exist
- Cancer registries also need to exist to diagnose and confirm the cancer

CONTACT US

For further information, or to request the Cervical Cancer Prevention and Control Costing Tool (C4PST), please contact: ncdsurveillance@who.int