Cancer
Prevention
Works

Operations, Research, and Technical Assistance (ORTAT) Overview

Toye Williams
NPCR Program Consultant

2019 NPCR Program Review Meeting

Atlanta, GA   April 24, 2019

CDC

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
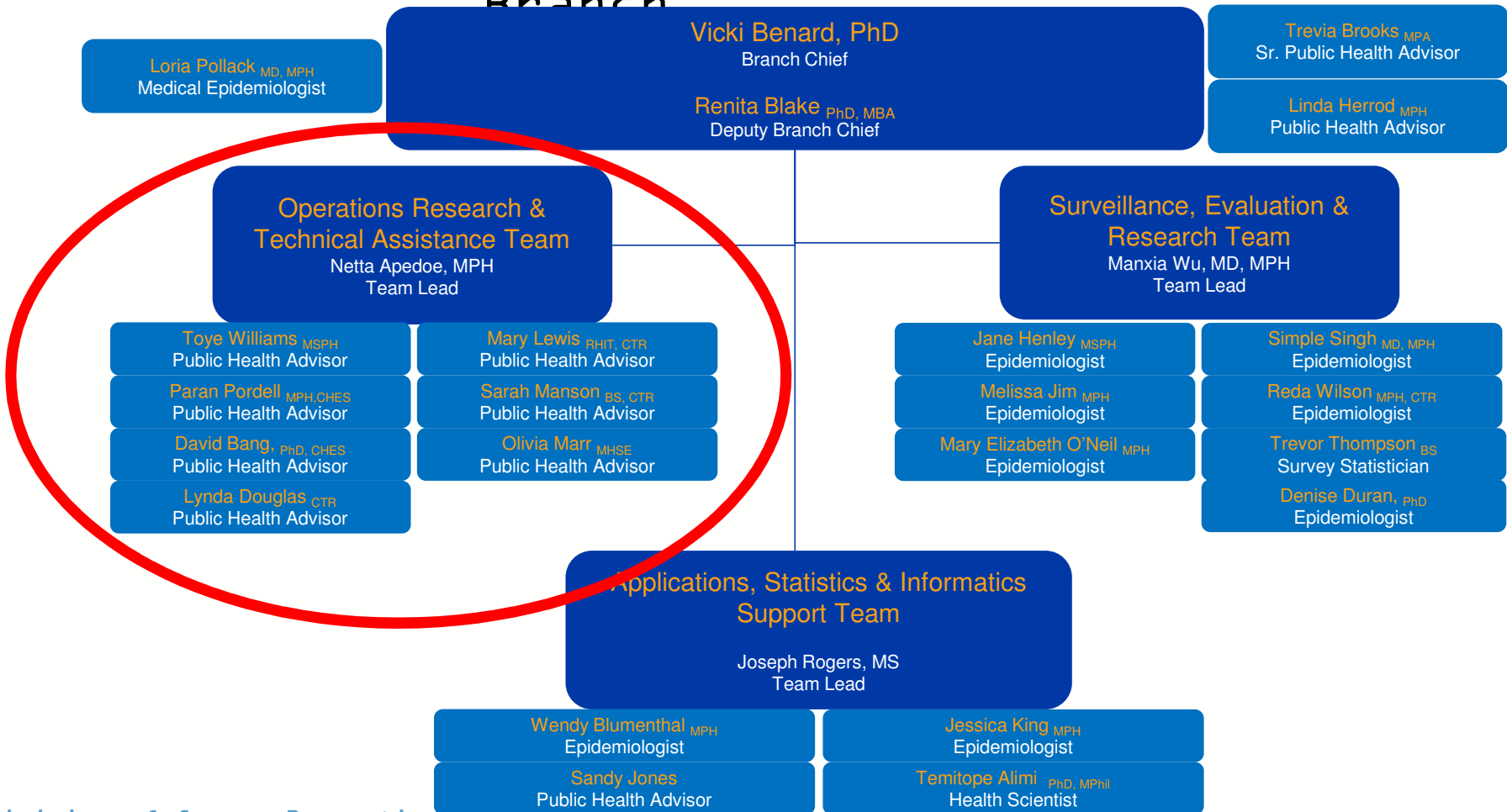Division of Cancer Prevention and Control

Objectives

- Overview of DP17-1701

- Overview NPCR Program Expectations

- ORTAT involvement

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Office of the Associate Director for Science

Nicole Dowling, PhD
Associate Director

Office of Management & Operations

Jason Dhonau
Program Management Official

Office of the Director

Lisa Richardson, MD, MPH
Director

Frances Babcock, BS, MT, CTR
Deputy Director

Office of Policy, Partnerships, and Communications

Mike Mizelle
Associate Director

Cancer Surveillance Branch

Vicki Benard, PhD
Branch Chief

Comprehensive Cancer Control Branch

Nikki Hayes, MPH
Branch Chief

Epidemiology & Applied Research Branch

Mary C. White, ScD
Branch Chief

Program Services Branch

Faye L. Wong, MPH
Branch Chief

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Cancer Surveillance Branch

Vicki Benard, PhD
Branch Chief

Renita Blake PhD, MBA
Deputy Branch Chief

Loria Pollack MD, MPH
Medical Epidemiologist

Trevia Brooks MPA
Sr. Public Health Advisor

Linda Herrod MPH
Public Health Advisor

Operations Research & Technical Assistance Team
Netta Apedoe, MPH
Team Lead

Toye Williams MSPH Public Health Advisor	**Mary Lewis** RHIT, CTR Public Health Advisor
Paran Pordell MPH,CHES Public Health Advisor	**Sarah Manson** BS, CTR Public Health Advisor
David Bang, PhD, CHES Public Health Advisor	**Olivia Marr** MHSE Public Health Advisor
Lynda Douglas CTR Public Health Advisor	

Surveillance, Evaluation & Research Team
Manxia Wu, MD, MPH
Team Lead

Jane Henley MSPH Epidemiologist	**Simple Singh** MD, MPH Epidemiologist
Melissa Jim MPH Epidemiologist	**Reda Wilson** MPH, CTR Epidemiologist
Mary Elizabeth O'Neil MPH Epidemiologist	**Trevor Thompson** BS Survey Statistician
	Denise Duran, PhD Epidemiologist

Applications, Statistics & Informatics Support Team
Joseph Rogers, MS
Team Lead

Wendy Blumenthal MPH Epidemiologist	**Jessica King** MPH Epidemiologist
Sandy Jones Public Health Advisor	**Temitope Alimi** PhD, MPhil Health Scientist

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Overview of DP17-1701 FOA

- Supports implementation of a comprehensive and coordinated approach

- Funds NBCCEDP, NCCCP, and NPCR

- Includes cross-cutting strategies

DP17-1701: Outcomes

- Increased survival

- Decreased incidence, morbidity, and mortality

- Reduced cancer risk

- Increased collaboration

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Coordination and Collaboration across Cancer Programs

NBCCEDP · CRCCP · NCCCP · NPCR
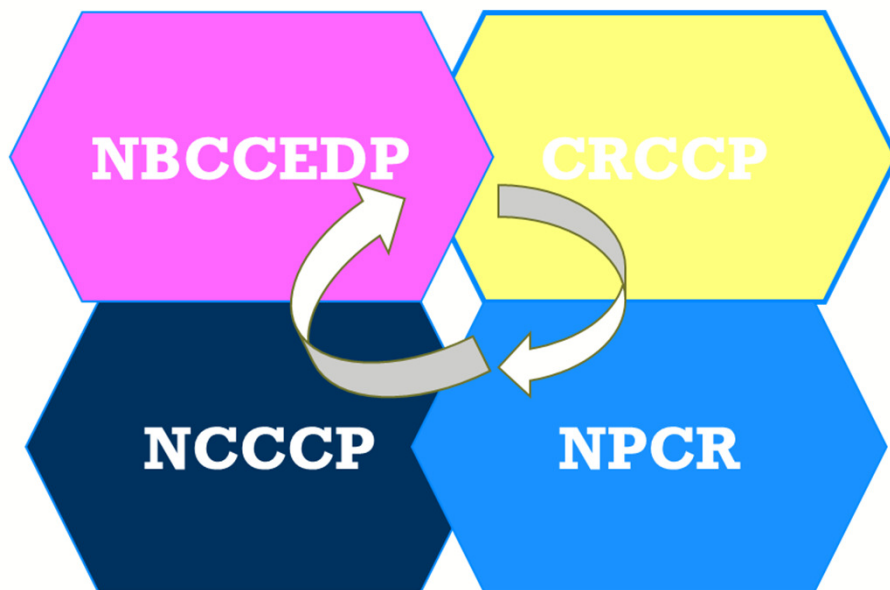
Cancer Leadership Team

- National Breast and Cervical Cancer Early Detection Program

- Colorectal Cancer Control Program (DP15-1502)

- National Comprehensive Cancer Control Program

- National Program of Cancer Registries

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Purpose of NPCR

"To support ongoing implementation of surveillance activities in the National Program of Cancer Registries by enhancing central cancer registry infrastructure to facilitate complete and timely cancer data."

NPCR Funded Central Cancer Registries

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NPCR Model

- Population-based cancer surveillance—reduce costs and expand data sets.

- Registry operations are not just about data collection and reporting.
  - Role of community engagement to support evidence based interventions.
  - Registry data findings help advocate policies for cancer prevention and control efforts.

NPCR Awardee FOA Compliance

Roles and Responsibilities

✓ Develop work plans and evaluation plans consistent with FOA

✓ Implement activities using approved work plans

✓ Continuously monitor progress and make program adjustments

✓ Submit required reports - FFRs, Annual Progress Reports, data submissions

✓ Communicate regularly with your Program Consultant

✓ Respond to CDC inquiries

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Awardee Requirements

✓Increasing coordination and collaboration with other cancer programs and chronic disease programs

✓**Develop biennial reports and submit final reports to CDC and share with partners**

✓Participate in ALL CDC-created and hosted analytic datasets and web-based systems outlined in the NPCR CSS Data Release Policy

✓Evaluation and Performance Measurement Plan

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Awardee Requirements

✓Improving capacity of NPCR Registries to receive physician cancer reports from Electronic Health Records (EHR)

➢Update existing state law/legislation to support electronic data exchange

➢ Develop and implement a plan to enhance timely reporting through electronic reporting and data exchanges

✓**Conduct National Death Index (recommended annually)**

✓Establish Interstate data exchange agreements with out-of-state registries and perform exchanges at least twice a year.

Data Driven Approach

- The NPCR work plan must be centered around NPCR standards for building the base for the central registry infrastructure.

- The registry operations must meet NPCR national standards to use data for betterment of improving the state cancer trends.

State, Regional and National Data Uses

- State cancer incidence reports.
- Comprehensive Cancer Control Plans.
- Response to state-level inquiries and requests.
- Assess disease risks, detection, and treatment locally.
- NPCR data---CDC submission (United States Cancer Statistics, Wonder, State Cancer Profiles.
- Report to the Nation
- Monographs

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Key Program Dates

July	September	October
• Beginning of fiscal year • Revised budgets	• Final Financial Report (FFR)	• Success stories • DQE activities begin (if applicable)

Key Program Dates

November	December/January	January
• 23-month data	• Continuation Notifications Released	• 12-month data submission

Key Program Dates

February	April	Others
• Prior approval requests • Continuation applications and annual reports	• Data Evaluation Reports(DERs) released	• Town Hall - Quarterly • Program Evaluation Instrument (PEI) - Biennially

NPCR Program Consultants

David Bang	**Region D, H, and VT**
Trevia Brooks	**Region I**
Lynda Douglas	**Region C**
Mary Lewis	**Region J**
Sarah Manson	**Region E**
Olivia Marr	**Region F, G**
Paran Pordell	**Region A**
Toye Williams	**Region B**

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Thank you!

Go to the official federal source of cancer prevention information:

www.cdc.gov/cancer

Cancer Prevention Works

Surveillance, Evaluation, and Research Team (SERT)

SERT Members

Denise Duran

Taylor Ellington

Jane Henley

Melissa Jim

Mary Elizabeth O'Neil

Virginia Senkomago
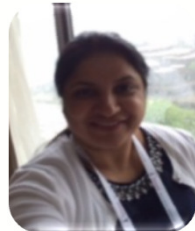
Simple Singh

Trevor Thompson

Reda Wilson

Manxia Wu

What SERT Does

Data Linkage:
NDI
IHS

CSS:
Data Submission

Data Quality Evaluation:
DQE, DER, PEI, DQI

Surveillance Enhancements:
CER, PCOR, Component Two

Surveillance

Evaluation

Research

Dissemination

Data Tools

Publications:
MMWR, ARN, Data Briefs, Special studies

U.S. Cancer Statistics:
Data Viz.
Public Data

U.S. Cancer Statistics
Official Federal Cancer Statistics

www.cdc.gov/uscs

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Public Use Database
U.S. Cancer Statistics

- **USCS data is publically available in two formats: Data Visualization tool and a Public Use Database**

- **Public Use Database contains population-based cancer incidence data from all 50 states and Puerto Rico**

- **Over 24 million cases and 15 years of data (cases diagnosed from 2001-2015)**

- **Researchers can access de-identified data at no cost through free software**

- **More information – www.cdc.gov/cancer/public-use**

National Program of Cancer Registries (NPCR) and Surveillance, Epidemiology & End Results (SEER)

NPCR and SEER Incidence – U.S. Cancer Statistics Public Use Database Data Standards and Data Dictionary

November, 2017 Submission
Diagnosis Years 2001–2015

CDC — U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

NIH — NATIONAL CANCER INSTITUTE
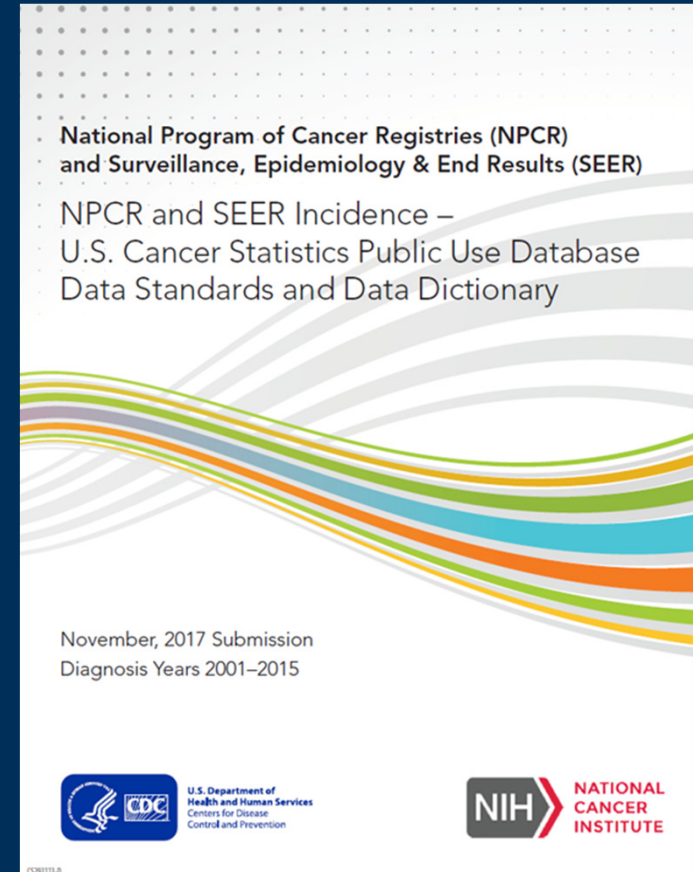
Data Visualizations Tool
## U.S. Cancer Statistics

- **The Data Visualizations tool makes it easy to explore and use the latest U.S. cancer data.**

- **Includes data on over 25 million cases, interactive graphics and data interpretations**

- **Explore the data –**
  - **New Cancer Cases & Cancer Deaths**
    - ✓ **By State and County**
    - ✓ **By Sex, Age, Race and Ethnicity**
  - **Cancer Trends (1999-2015)**
  - **National Cancer Prevalence Estimates**
  - **5-year Relative Survival Estimates**
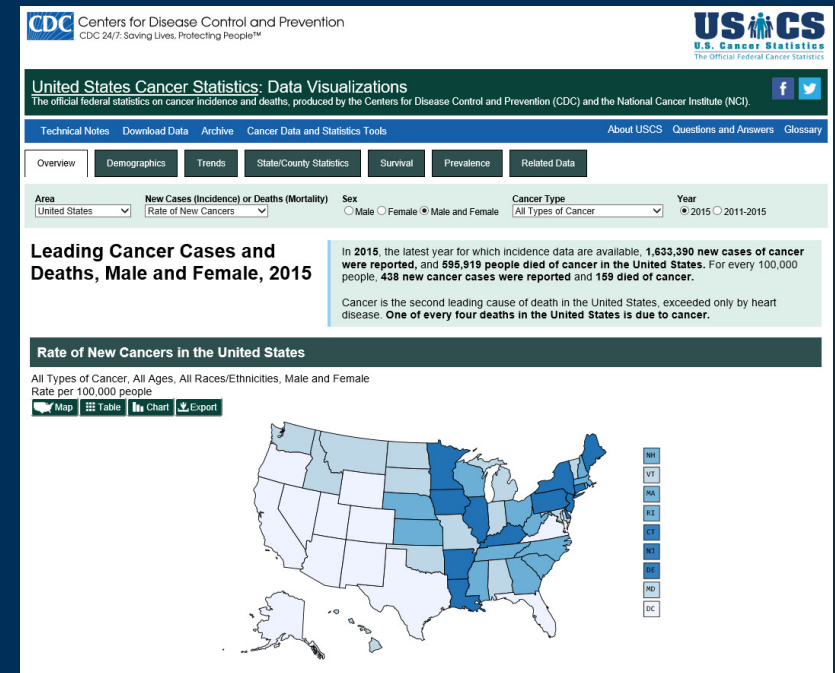
www.cdc.gov/cancer/dataviz

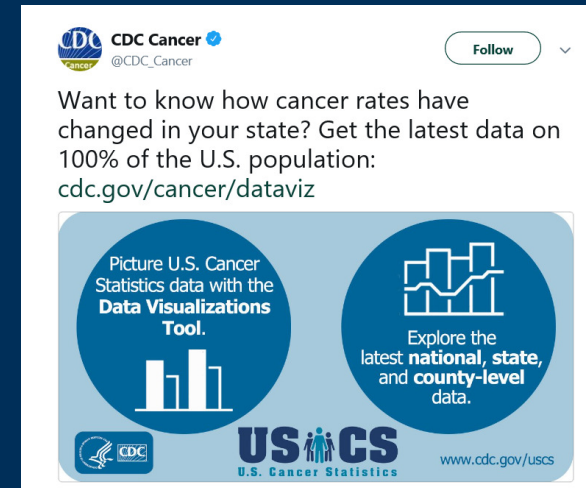# Data Visualizations Tool – data is accessible
U.S. Cancer Statistics
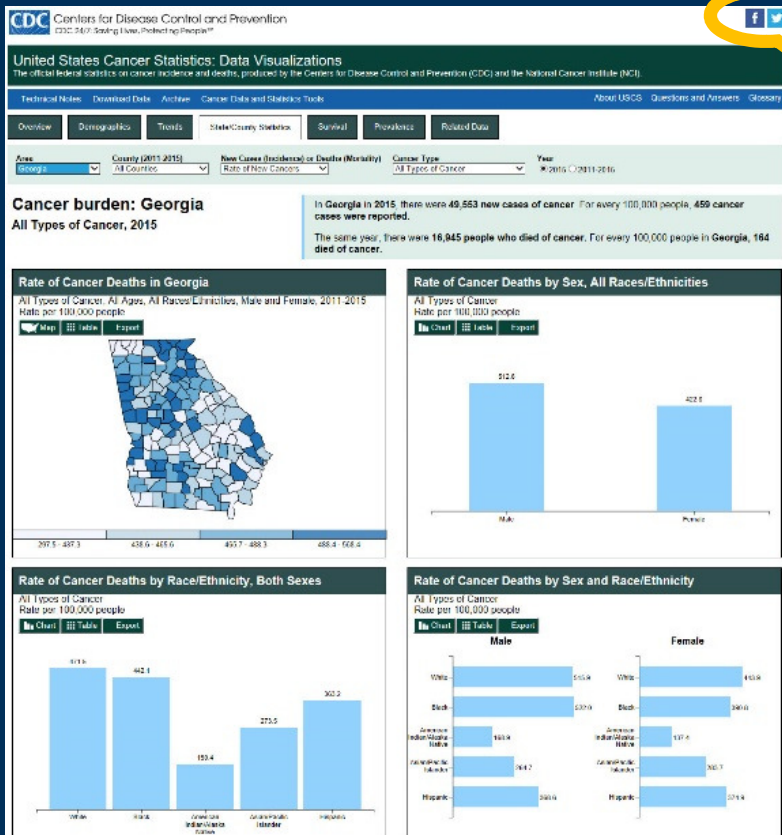
Share data visualizations on social media and use in presentations!

- Selections are saved

- Extends data sharing

- Great way to highlight

  data

- Facebook or Twitter
  - #Cancer
  - #DataViz
  - #USCS

www.cdc.gov/cancer/dataviz

USCS New Modules Added

Modules added in 2018:

- Data on expanded cancer sites
- County Level Data
- Prevalence Estimates
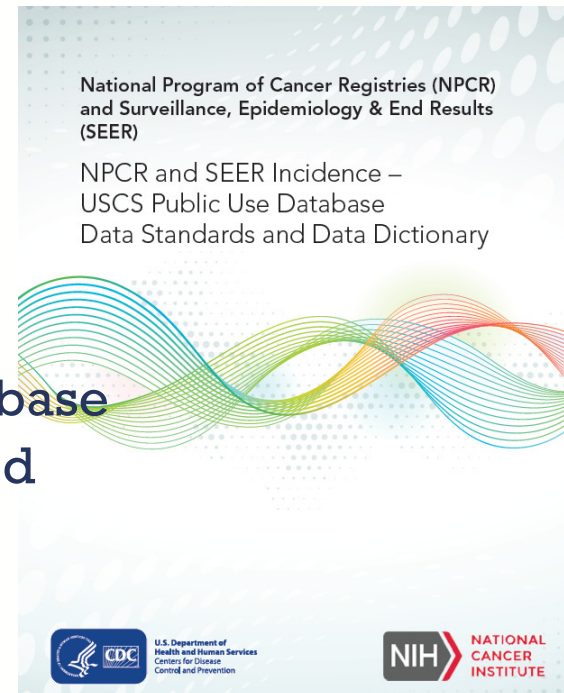- Congressional Level District Estimates

Modules to be added in 2019:

- Addition of data on American Indians/Alaskan Natives
- Risk Factor –Associated Cancers:
    Obesity, Alcohol, HPV, Tobacco

Public Use Databases – 2018 Metrics
U.S. Cancer Statistics

- **155** requests for access
  - ~50% academic or medical researcher
    23% cancer or public health partner
    22% pharma or private sector
  - 57% of users are new – no access to last year's database
  - 39 academic and 14 medical institutions represented

- **9** publications from extramural researchers

- Nearly **30k** page views
  - October – 300% more unique visitors compared to previous year

National Program of Cancer Registries (NPCR) and Surveillance, Epidemiology & End Results (SEER)

NPCR and SEER Incidence – USCS Public Use Database Data Standards and Data Dictionary

CDC — U.S. Department of Health and Human Services Centers for Disease Control and Prevention

NIH — NATIONAL CANCER INSTITUTE

www.cdc.gov/cancer/public-use

Demonstrations
https://www.cdc.gov/cancer/

U.S. Cancer Statistics
Official federal cancer statistics

- **The Data Visualizations tool displays U.S. Cancer Statistics data with interactive graphics and data interpretations**

- **Data is accessible to the general public, media, policy makers and planners**

- **The tool is being continuously improved to enhance accessibility and provide more data**

- **More Information – www.cdc.gov/uscs | uscsdata@cdc.gov**
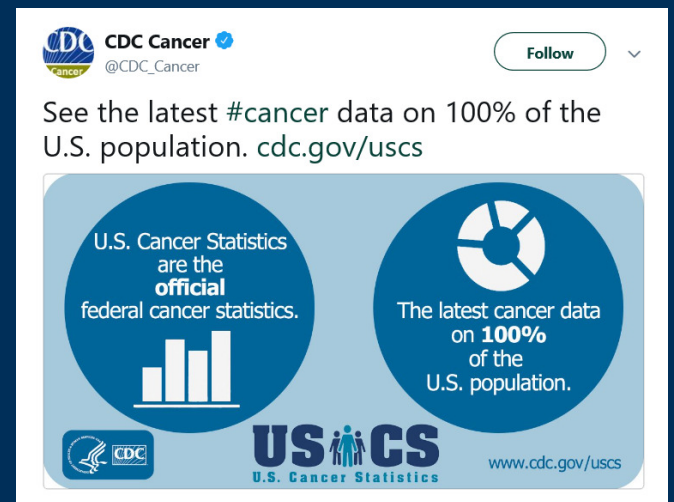
What does IDSAT do?

Informatics

- The science concerned with gathering, manipulating, storing, retrieving, and classifying recorded information.

- *Public health informatics* is "…the systematic application of information and computer science and technology to public health practices, research and learning." It is the efficient and effective organization and management of data, information, and knowledge generated and used by public health professionals to fulfill the core functions of public health—assessment, policy, and assurance.

Cancer Surveillance System Modernization

Informatics Activities—

Electronic Pathology and Bio-Marker Reporting

- Implement automated, electronic reporting
- Standard HL7 format for narrative and structured reports
- IDSAT team works with laboratories and states to implement

Electronic Physician Reporting and Meaningful Use

- Implement automated, electronic reporting
- Standard HL7 format for physician reports from Electronic Health Record (EHR) systems
- IDSAT Team works with EHR vendors and states to implement

Mortality Interoperability Project

- Part of larger CDC National Center for Health Statistics (NCHS) initiative to improve the quality of the National Vital Statistics System (NVSS)
- State cancer registries will be able to receive mortality reports within two days of the State Vital Records Office receiving a coded death certificate

Standards Development

- Work closely with state cancer registries and NAACCR to develop electronic reporting standards
- Keep up with current standards and technologies to identify best options for cancer reporting standards

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What does IDSAT do?

Data Science

A multi-disciplinary field that uses scientific methods, processes, algorithms, and systems to extract knowledge and insights from structured and unstructured data.
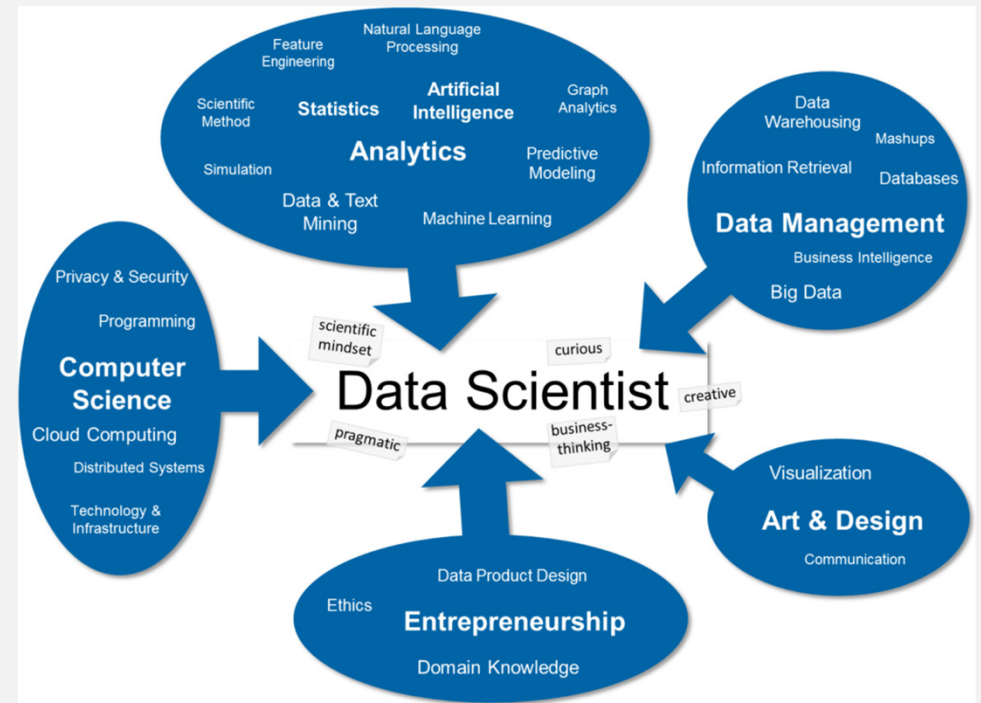
What does IDSAT do?

Data Science Activities—Highlights

Cloud-Based Computing Platform

- Real-time reporting
- Services to automate processing and coding, deduplication/consolidation, follow-back, and others.

Natural Language Processing (NLP)/Machine Learning

- Auto-coding of key cancer data elements from text-based pathology reports (current)
- Automated determination of reportability for text-based pathology reports (in development)
- Auto-coding of key cancer data elements from text content in EHR reports (planned)

Division and Branch Analytic/Statistical Support

What does IDSAT do?

Applications: Registry Plus

Publically available free software programs that are:

- used to collect and process cancer registry data
- compliant with national standards, are made available by CDC to implement the National Program of Cancer Registries (NPCR)
- developed and enhanced with significant registry user input
- See NPCR website for additional information: https://www.cdc.gov/cancer/npcr/tools/index.htm

CRS Plus

- Main central registry database program
- Supports the linkage of incoming abstracts against the existing database, with software-assisted consolidation into patient and tumor tables

TLC Plus

- Optional, rules-based, automated tumor linkage and consolidation function for CRS Plus
- Determines multiple primary tumors automatically.
- Consolidates data items from multiple case reports into tumor records

Abstract Plus

- Used to summarize medical records into an electronic report of cancer diagnosis and treatment by abstractors or anyone working with cancer data

What does IDSAT do?

Applications

eMaRC Plus: Electronic Mapping, Reporting, and Coding

- Pathology and physician modules
- Builds a pathology laboratory and physician databases and stores HL7 data elements as discrete field values in tables
- Creates NAACCR-formatted abstract records from pathology and physician reports during import
- Maps and auto-populates the abstract with data received in the pathology or physician report

Web Plus

- Web-based application that collects cancer data securely over the public Internet
- Supports online abstracting, file upload and download, and follow-back efforts

Prep Plus

- Logs in abstracts and begins a tracking system for incoming records
- Applies standard NAACCR edit checks
- Allows further visual inspection of submitted records and error correction

Link Plus

- Probabilistic record linkage program

CDA Validation Plus

- Validates structure, content, codes, and coding systems of HL7 Clinical Document Architecture (CDA) documents generated by EHR software systems

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What does IDSAT do?

Technical Assistance and Subject Matter Expert Support

Subject Matter Expert (SME) Support
- Certified Tumor Registrars (CTRs)
- Prepare user documentation, provide training, advise users on best ways to use the software, and help troubleshoot problems that arise
- Refine application enhancement requests
- Contribute heavily to development and maintenance of the applications
- NAACCR Workgroup support

Technical Assistance
- Work closely with labs (ePath) and EHR vendors (physician) to meet HL7 standards
- Assist states with processing and validation of lab and physician reports
- Provide software training and support
- Provide registry operations support in context of Registry Plus applications

Help Desk
- CancerInformatics@cdc.gov
- First response within one hour (during normal business hours)
- Three-tiered support

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Workgroups/Meetings/Training

Registry Plus User Group (RPUG)[1]

- Communicate software updates and discuss development plans with users

- Promote exchange of software issues, successes, and ideas for implementation

- Monthly web-based meetings

Electronic Pathology Workgroup (ePath)[1]

- Communicate software updates and discuss development plans with users

- Provide updates on laboratory implementations

- Obtain user input on specific issues and software enhancements

- Quarterly web-based meetings

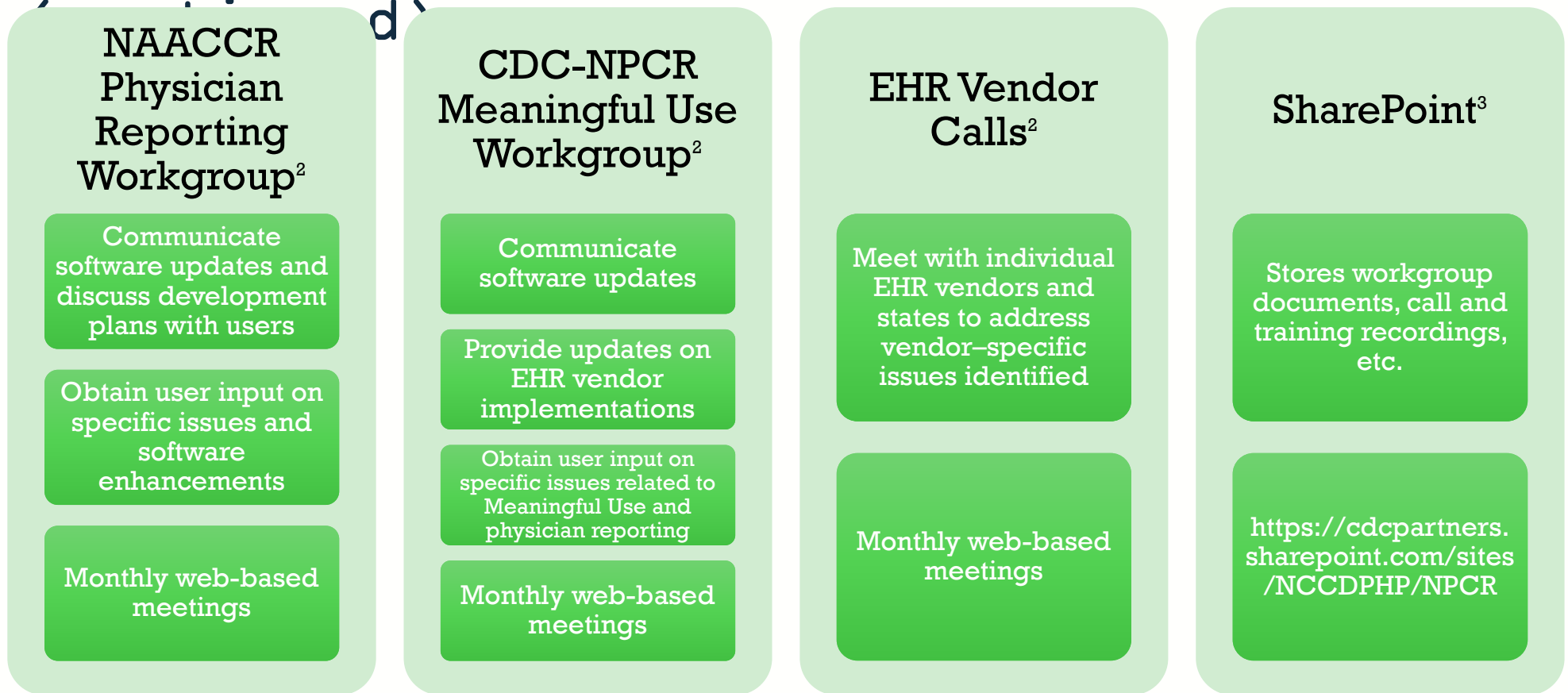## eMaRC Plus Pathology Lab Reporting Brown Bag Webinar Series

- 30-minute tutorials on how to use a feature in the eMaRC pathology module

- Informal monthly webinar series

- All recordings available on ePath SharePoint site

[1]Contact Jen Wike (bhn9@cdc.gov)

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Workgroups/Meetings/Training Tools (continued)

NAACCR Physician Reporting Workgroup[2]

- Communicate software updates and discuss development plans with users
- Obtain user input on specific issues and software enhancements
- Monthly web-based meetings

CDC-NPCR Meaningful Use Workgroup[2]

- Communicate software updates
- Provide updates on EHR vendor implementations
- Obtain user input on specific issues related to Meaningful Use and physician reporting
- Monthly web-based meetings

EHR Vendor Calls[2]

- Meet with individual EHR vendors and states to address vendor–specific issues identified
- Monthly web-based meetings

SharePoint[3]

- Stores workgroup documents, call and training recordings, etc.
- https://cdcpartners.sharepoint.com/sites/NCCDPHP/NPCR

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www.cdc.gov/cancer

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