#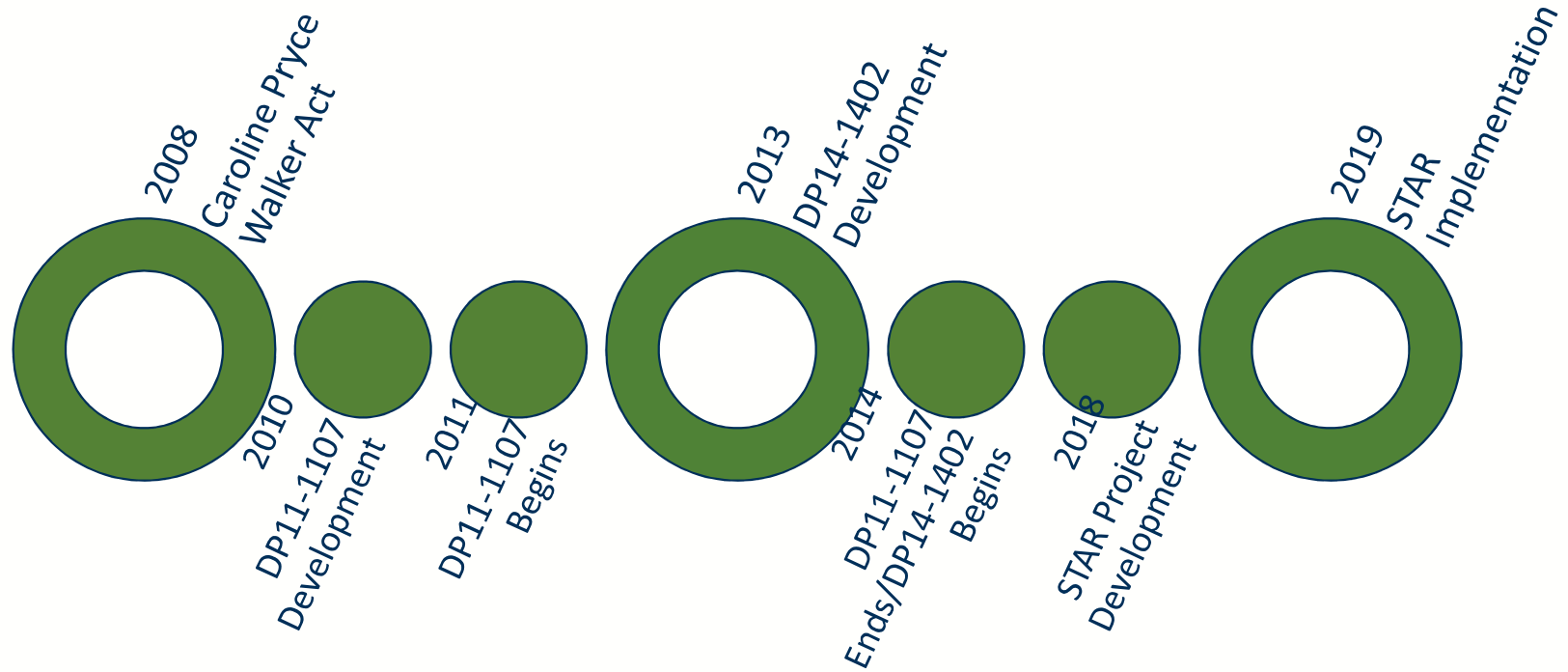 Early Case Capture of Pediatric and Young Adult Cancers (ECC) and Childhood Cancer Survivorship, Treatment, Access, and Research (STAR)

Cancer Prevention Works

Toye Williams
Project Lead

NPCR Program Review Meeting
April 24, 2019

OVERVIEW OF ECC

2008 Caroline Pryce Walker Act

2010 DP11-1107 Development

2011 DP11-1107 Begins

2013 DP14-1402 Development

2014 DP11-1107 Ends/DP14-1402 Begins

2018 STAR Project Development

2019 STAR Implementation

Caroline Pryce Walker Conquer Childhood Cancer Act of 2008

CDC shall award a grant to:

- Enhance and expand infrastructure to track epidemiology of pediatric cancer into a comprehensive nationwide registry

- Include actual occurrences of pediatric cancer within weeks of the date of such occurrence

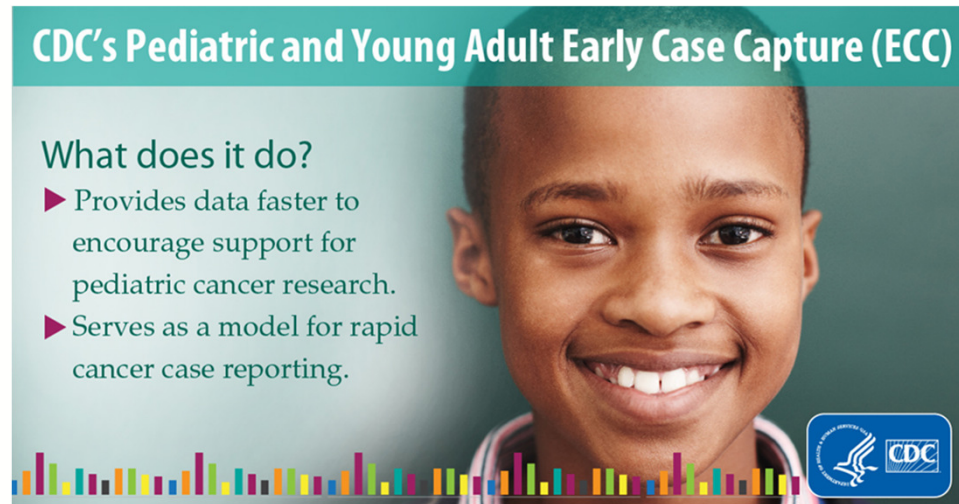# Early Case Capture of Pediatric and Young Adult Cancers (ECC) Project

DP 11-1107	DP14-1402
3-Year Project : 9/30/2011-9/29/2014	5-Year Project : 9/30/2014 – 9/29/2019
Cancer Registries Awarded: CA, KY, LA, MN, NE, NY, OK	Cancer Registries Awarded: KY, LA, MN, NE, NY, RI, WI
Overall Goals (Caroline Pryce Walker Act) • Enhance infrastructure • Report cases • Increase availability of data	

ACTIVITES

Division for Cancer Prevention and Control

Reliable. Trusted. Scientific.

Awardee Activities

- Facilitate rapid reporting
- Expand reporting relationships with facilities
- Monitor data quality, completeness, and timeliness
- Increase availability of pediatric data
- Bi-annual submissions

CDC's Pediatric and Young Adult Early Case Capture (ECC)

What does it do?
- Provides data faster to encourage support for pediatric cancer research.
- Serves as a model for rapid cancer case reporting.

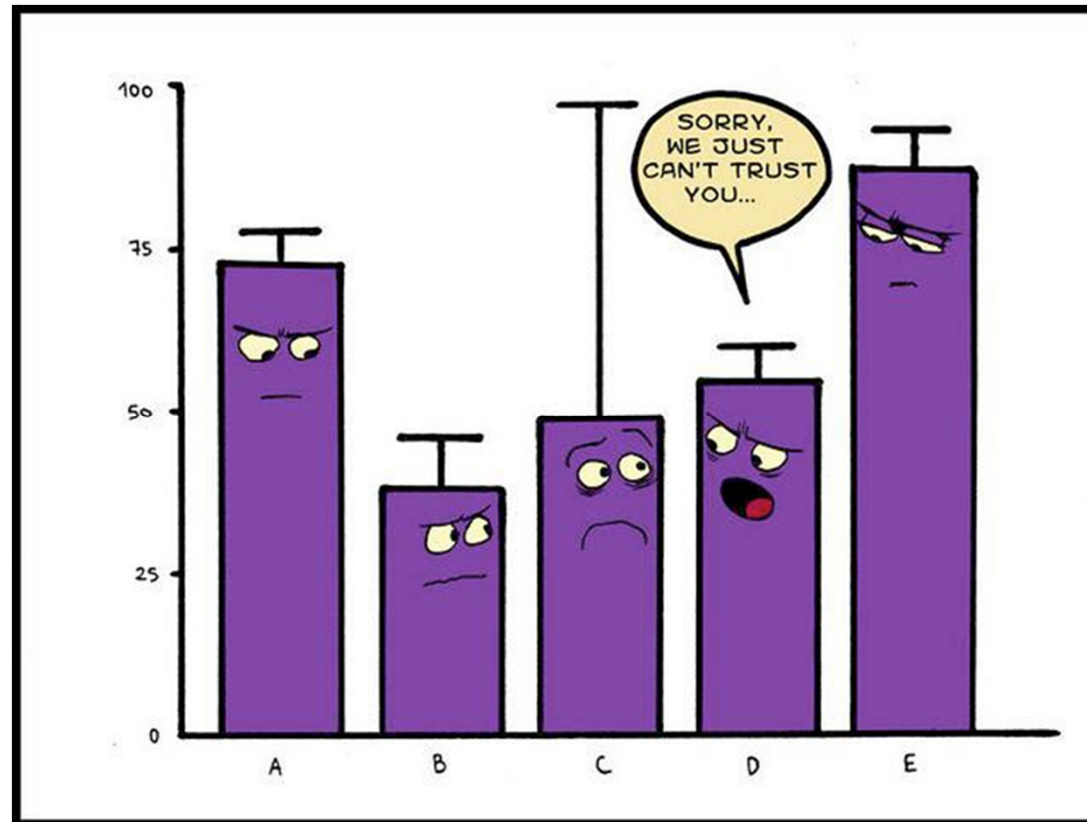Reliable. Trusted. Scientific.

Required Data Items

• All reportable cancers and benign brain and CNS tumors diagnosed January 1, 2015 forward, age 0-19.

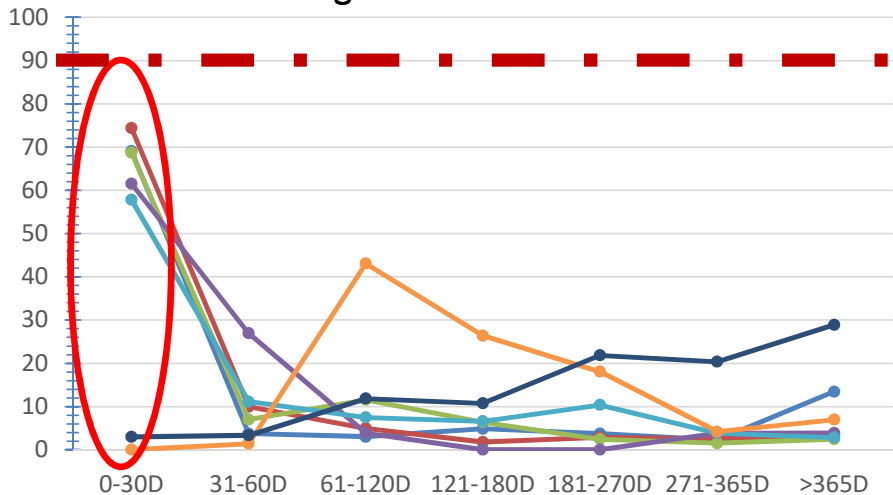| Demographics	Follow-back Info	Diagnostic Info
Last Name	Physician Address	Primary Site
First Name	Physician Phone #	Histology
Birth Date	Patient Address Current	Behavior
Age at DX	Patient Phone Number	Laterality
Social Security #	Follow-up Contact	Date of Diagnosis
Address at DX		Date of 1st Contact
Race 1-5		Diagnostic Conf.
Spanish/Hispanic Orig.		Sequence Number
Sex		Type of Rpt. Source

Key Outcome Measures

- Data completeness, quality, and timeliness
  - 95% complete, 99% pass edits, 1/1,000 duplicates, 1% missing age, 1% missing sex, 2% missing race, 1% missing county
  - Timeliness: 90% of cases received at CCR within 30 days
- Case-finding audits of reporting hospitals
  - Once every 2 years
- Data submission to CDC twice a year, within 4 months
  - Edited, consolidated data with consistent, unique patient ID
  - Complete submission forms, including calculation of timeliness
  - April: Cases from January-December of previous year
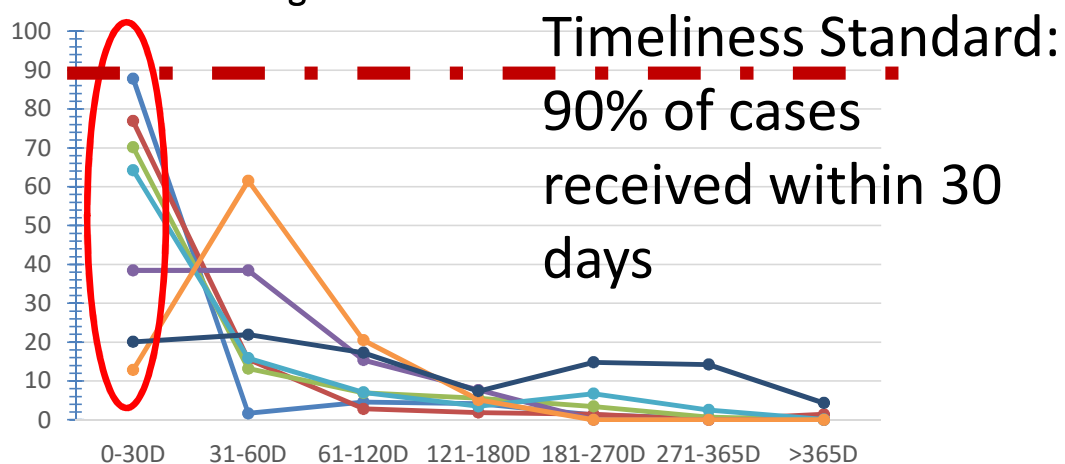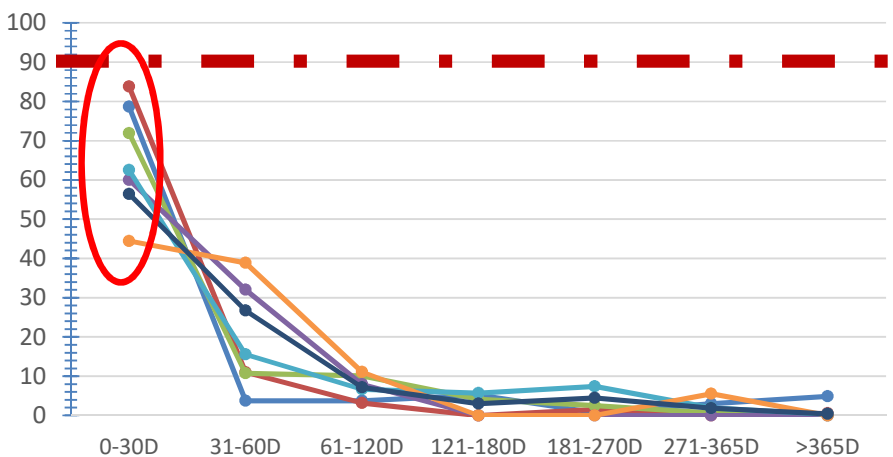 - October: Cases from January-June of that year

Reliable. Trusted. Scientific.

DATA

Division for Cancer Prevention and Control   Reliable. Trusted. Scientific.

Timeliness in Diagnosis Year 2015

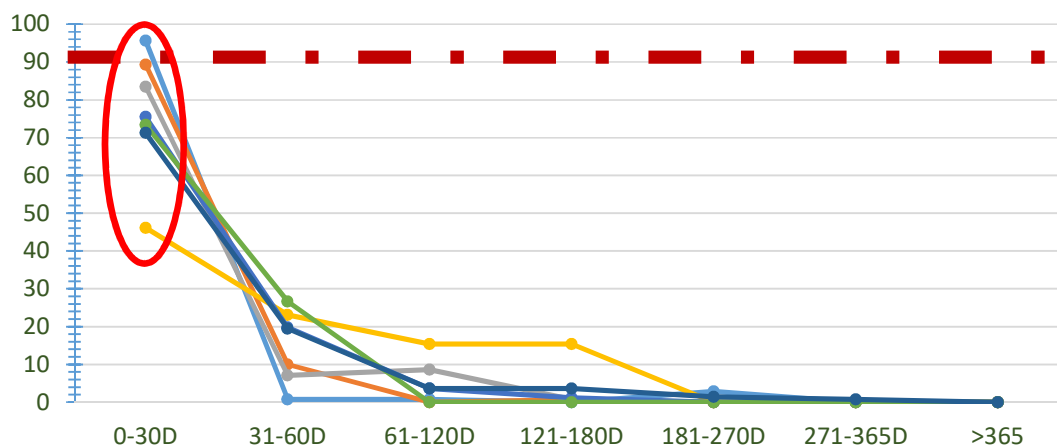Timeliness in Diagnosis Year 2016

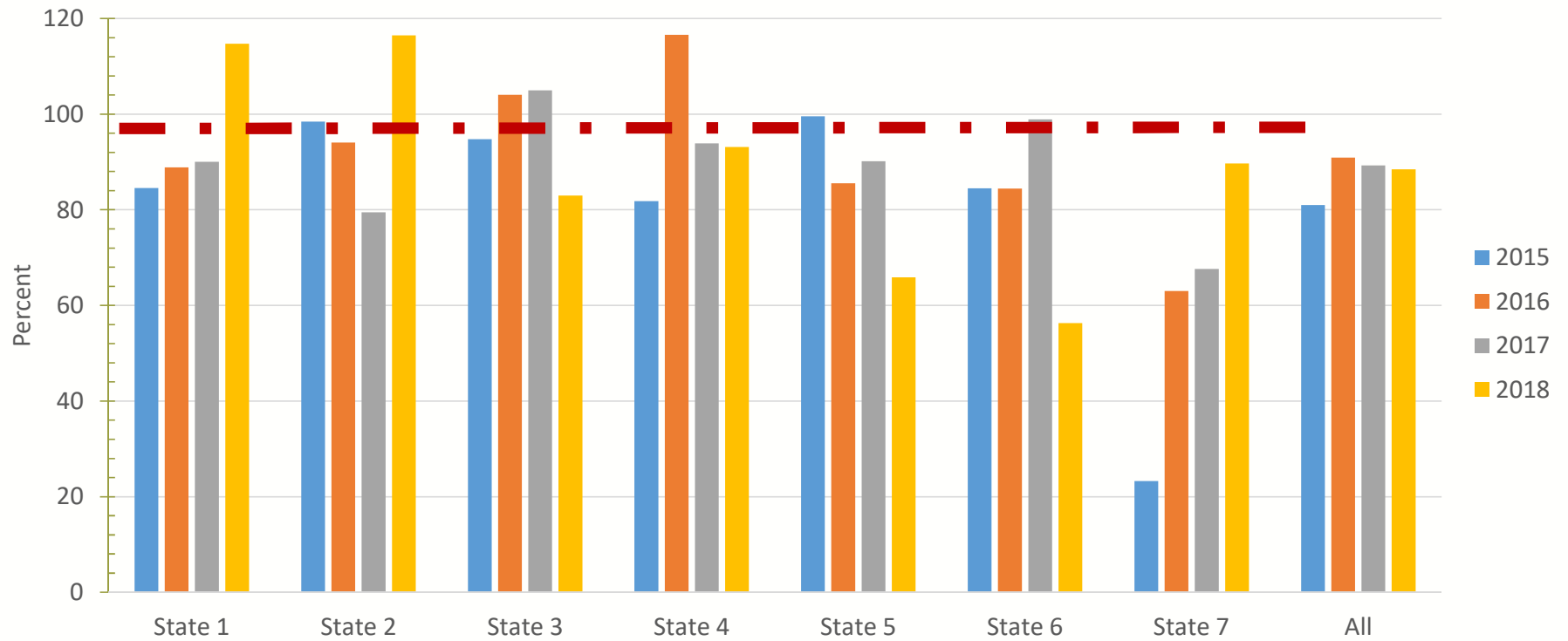Timeliness Standard: 90% of cases received within 30 days

Timeliness in Diagnosis Year 2017

Timeliness in Diagnosis Year 2018
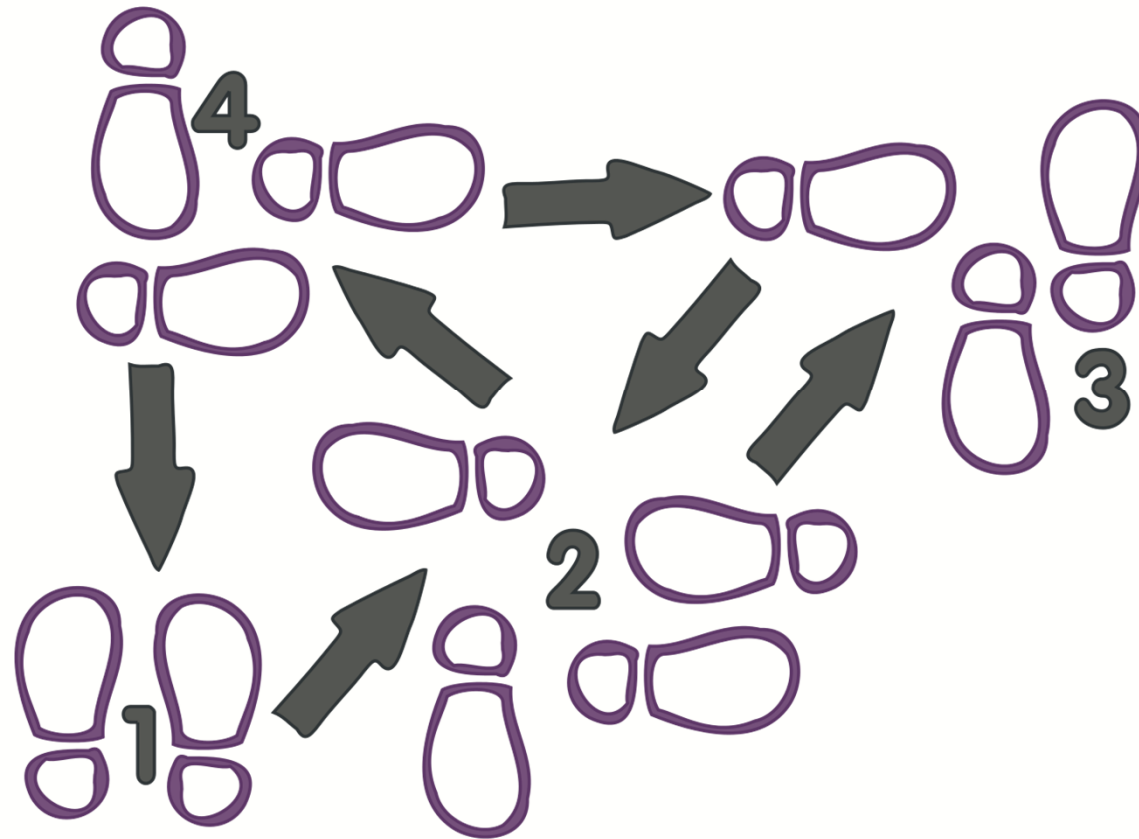
January-June Completeness

October Submissions

January-December Completeness

April Submissions

Reliable. Trusted. Scientific.

NEXT STEPS

Reliable. Trusted. Scientific.
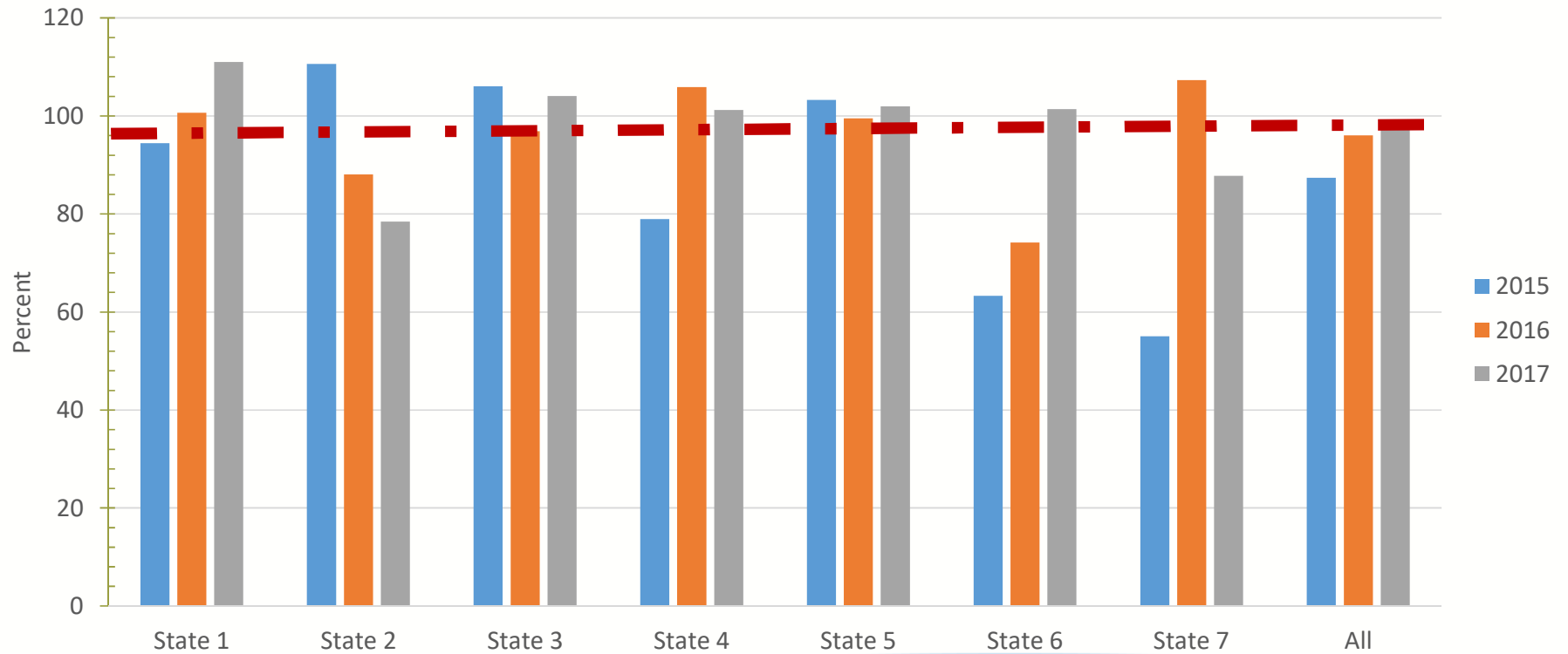
Survivorship, Treatment, Access, and Research Act of 2018 (STAR)

Childhood Cancer
STAR ACT
Survivorship Treatment Access and Research

Congress has authorized CDC to:

1. Identify, recruit, and train potential sources for reporting cases.

2. Develop practices to ensure early inclusion of cases in State cancer registries through electronic reporting.

3. Collect and submit de-identified data to CDC for inclusion in a national database.

4. Improve State cancer registries and the database, as appropriate, including to support the early inclusion of PAYAC cases

Cancer Data Modernization

- Improving our cancer registry system's ability to capture electronic pathology reports for ALL cancers INCLUDING pediatric cancers

- Continue working with the states to improve timeliness and completeness of these cases within 30 days

- Strengthen relationships with key partners such as NCI and the Children's Oncology Group hospitals

Future Vision

- Electronically send first diagnosis of cancer to the platform

- Automate in platform

- One process for all states

- Real-time reporting and more efficient data processing

Division for Cancer Prevention and Control

Reliable. Trusted. Scientific.
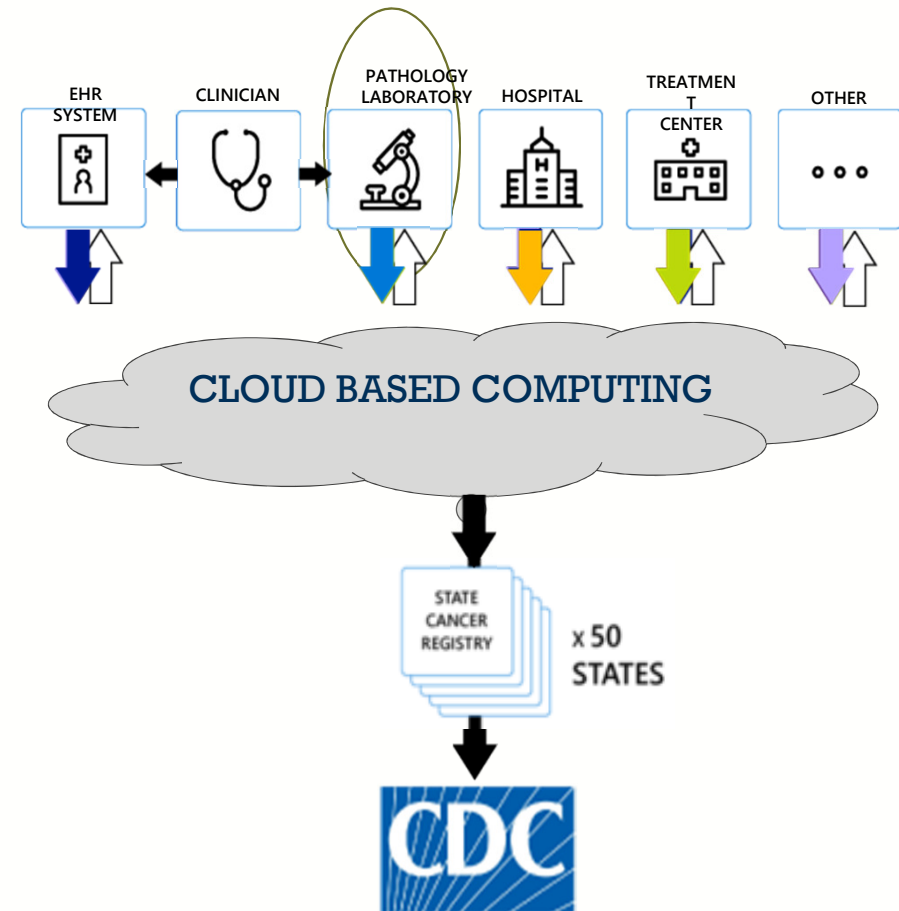
Value of the Cloud: Real-time Data

- Enable faster reporting of all cancer cases
  - Including pediatric and young adult cancers

- Find out what interventions work

- Inform resources allocation

- Timely identification for clinical trials

- Identify research priorities more quickly

Central Cancer Registries

Kentucky Cancer Registry
Louisiana Tumor Registry
Minnesota Cancer Surveillance System
Nebraska Cancer Registry
New York State Cancer Registry
Rhode Island Cancer Registry
Wisconsin Cancer Reporting System

ICF Macro

CDC Staff

Netta Apedoe
David Bang
Dr. Vicki Benard
Dr. Renita Blake
Wendy Blumenthal
Lynda Douglas
Linda Herrod
Sandy Jones
Jessica King
Mary Lewis
Sarah Manson
Olivia Marr
Dr. Loria Pollack
Paran Pordell
Joe Rogers
Dr. David Siegel
Dr. Eric Tai
Reda Wilson
Dr. Manxia Wu

Thank you!

Go to the official federal source of cancer prevention information:

www.cdc.gov/cancer

Cancer
Prevention
Works

Reliable. Trusted. Scientific.