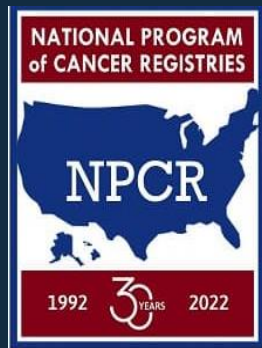




CDC STAR Project

Survivorship, Treatment, Access, and Research

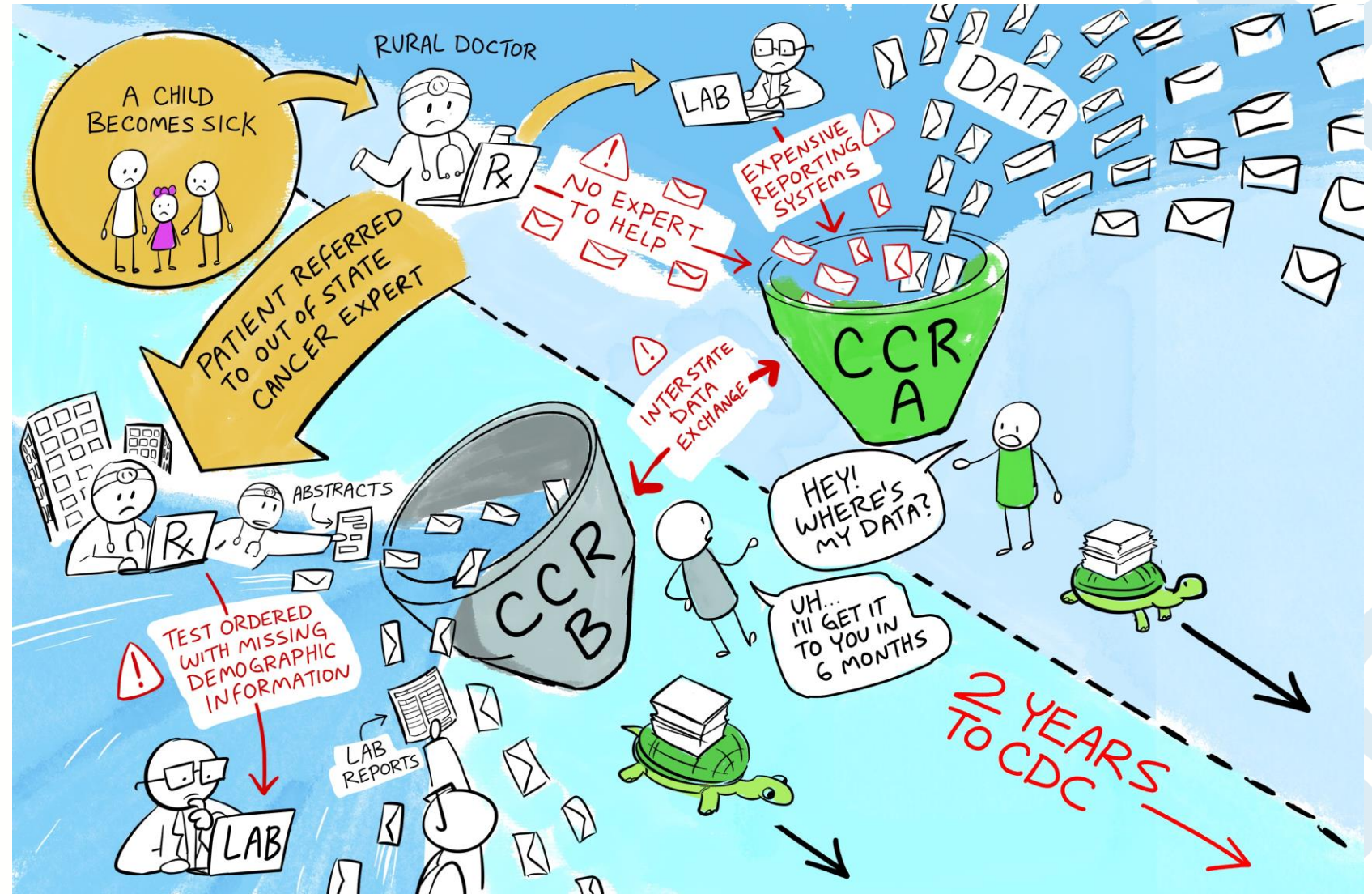


Loria Pollack, MD, MPH
Centers for Disease Control and Prevention
Division of Cancer Prevention and Control, Cancer Surveillance Branch

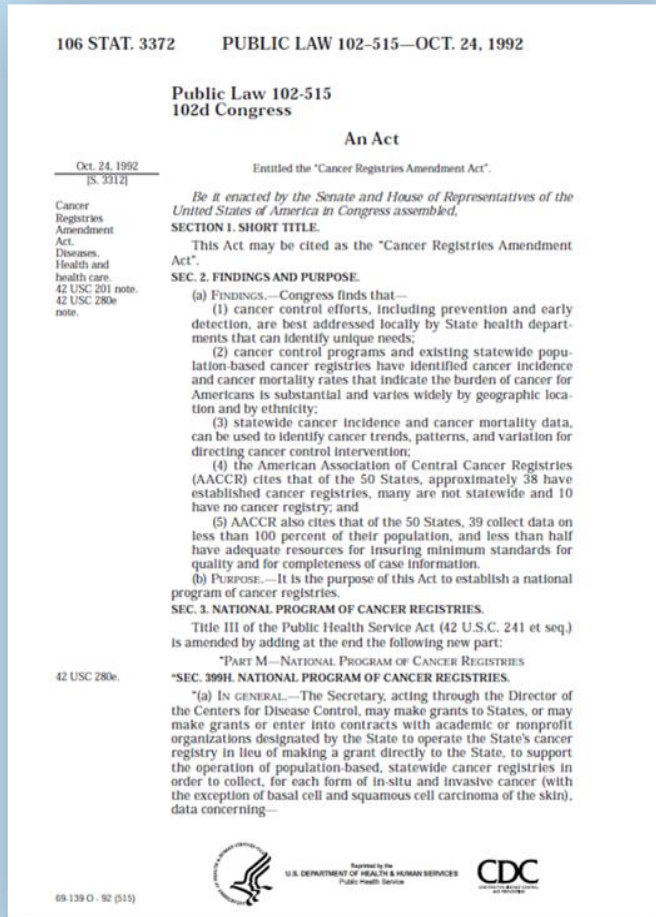
Florida Cancer Data Systems 2022 Annual Training
August 25, 2022



Current Landscape of Reporting



The Childhood Cancer Survivorship, Treatment, Access, and Research Act (STAR)



- ★ Milestone, bipartisan legislation enacted in 2018
- ★ Designed to advance understanding and care of cancer diagnosed in children, adolescents, and young adults
- ★ CDC was charged to “enhance and expand infrastructure to track the epidemiology of cancer in children, adolescents, and young adults”



STAR Project Goals

- Expand **rapid case reporting** from facilities where childhood cancer is diagnosed into cancer registries
- Develop and implement an **infrastructure** to support early inclusion of childhood cancer to registries
- Provide **timely data** to improve understanding and lives of children, adolescent, and young adults diagnosed with cancer

CDC STAR Project



- Designed and led by **CDC National Program of Cancer Registries (NPCR)**
- Contracted to **Tanaq Support Services**
 - Working directly with laboratories and state central cancer registries

CDC STAR Project



Timely Data on
Childhood Cancer

Rapid Case Reporting



Laboratories
Reporting Sources

State-based
Central Cancer Registries

NPCR-NOAH

National Program of Cancer Registries
National Oncology rapid Ascertainment Hub

Rapid case reporting

- ★ Expand rapid case reporting from facilities where childhood cancer is diagnosed into cancer registries
- ★ Develop and implement an infrastructure to support early inclusion of childhood cancer to registries
- ★ Provide timely data to improve understanding and lives of children, adolescent, and young adults diagnosed with cancer



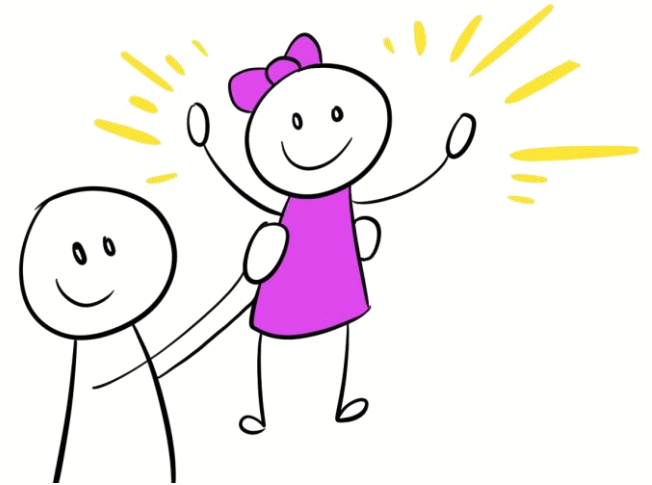
STAR Rapid Case Reporting

- Who**
 - All reporting facilities that diagnose or treat patients aged 0-29
- What**
 - Partial abstracts / Suspense List
 - Patients aged 0-29
 - Minimum data set
 - Diagnosed on or after Jan 1, 2020
- When**
 - Routine submissions
 - Earlier than 6 months
- Where**
 - Submission to Central Cancer Registry (CCR)
- How**
 - Processes to be defined with CCR

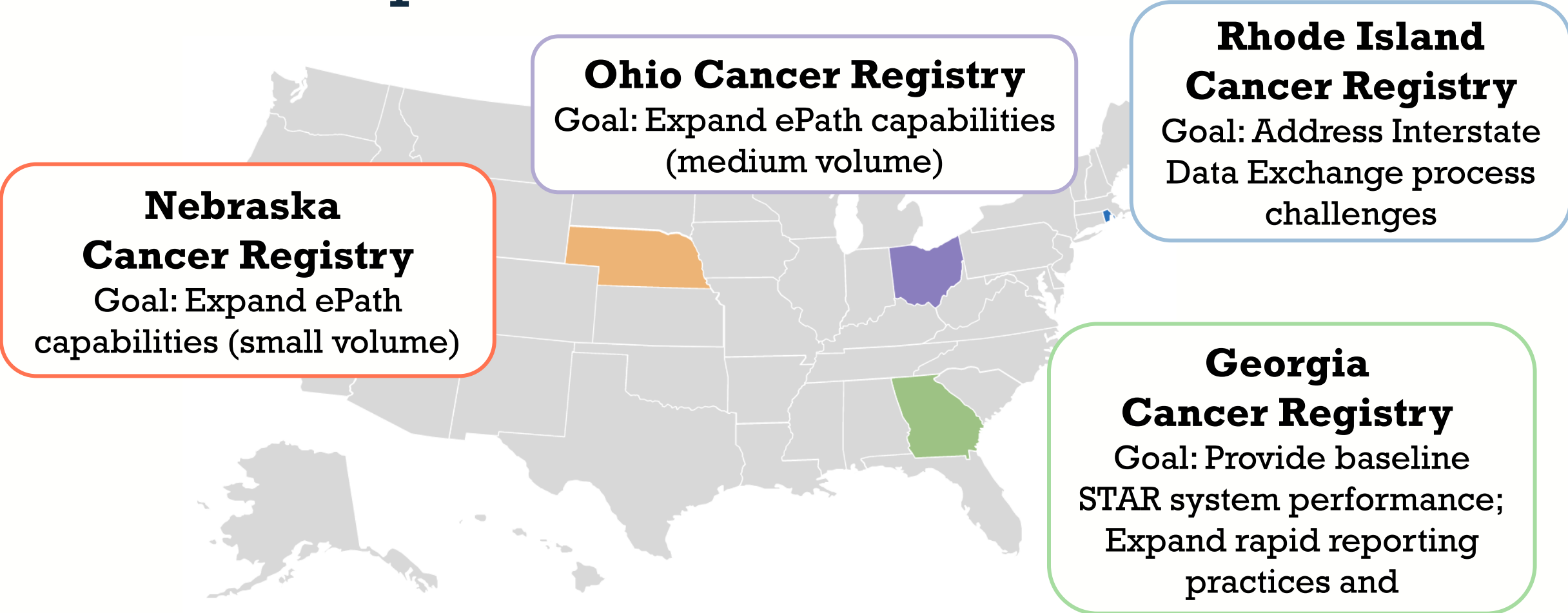


Centralized CTR Support

- ★ CTR support determined based on individual state CCR needs and defined project scope
- ★ Activities may include:
 - ★ Reportability assessment
 - ★ Electronic pathology (ePath) submission review, coding, and case-finding audits
 - ★ NPCR-NOAH reportability and auto-coding evaluation and feedback
 - ★ Follow back



State Participants



**Nebraska
Cancer Registry**
Goal: Expand ePath capabilities (small volume)

Ohio Cancer Registry
Goal: Expand ePath capabilities (medium volume)

**Rhode Island
Cancer Registry**
Goal: Address Interstate Data Exchange process challenges

**Georgia
Cancer Registry**
Goal: Provide baseline STAR system performance; Expand rapid reporting practices and

CDC STAR Project
**Reporting
Source
Participants**



A Variety of Reporting Sources

- Independent labs
- Hospital labs
- Health Information Exchanges
- Hospital Cancer Registries

Facilities with Rapid Reporting Processes in Place

- 27 in Nebraska
- 9 in Rhode Island
- 5 in Ohio

Facilities Assessing STAR Project Participation

- 1 Health Information Exchange
- 2 Healthcare System Laboratories
- 4 Independent Laboratories

CDC STAR Project

Rapid Case Reporting

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National Oncology rapid Ascertainment Hub



NPCR-NOAH

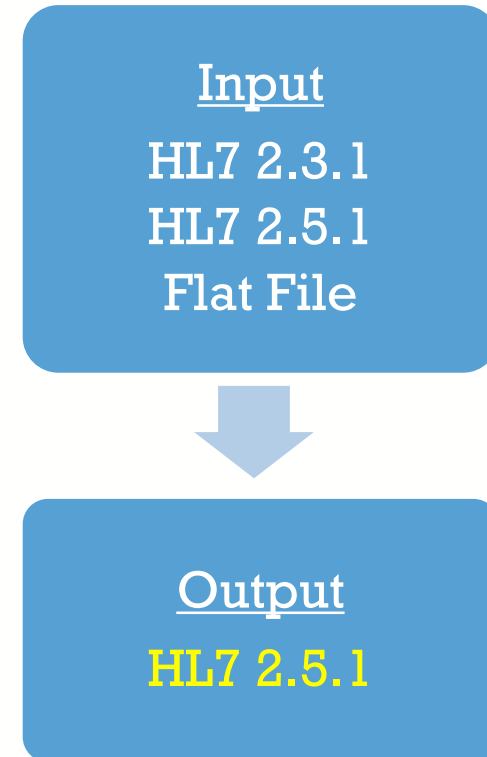


- An infrastructure to support early inclusion of childhood cancer in registries
- Cloud-based informatics system to improve case finding, reportability, and timeliness of cancer in
 - Children
 - Adolescents
 - Young Adults
- Centralized electronic rapid case reporting from laboratories into state-based registries

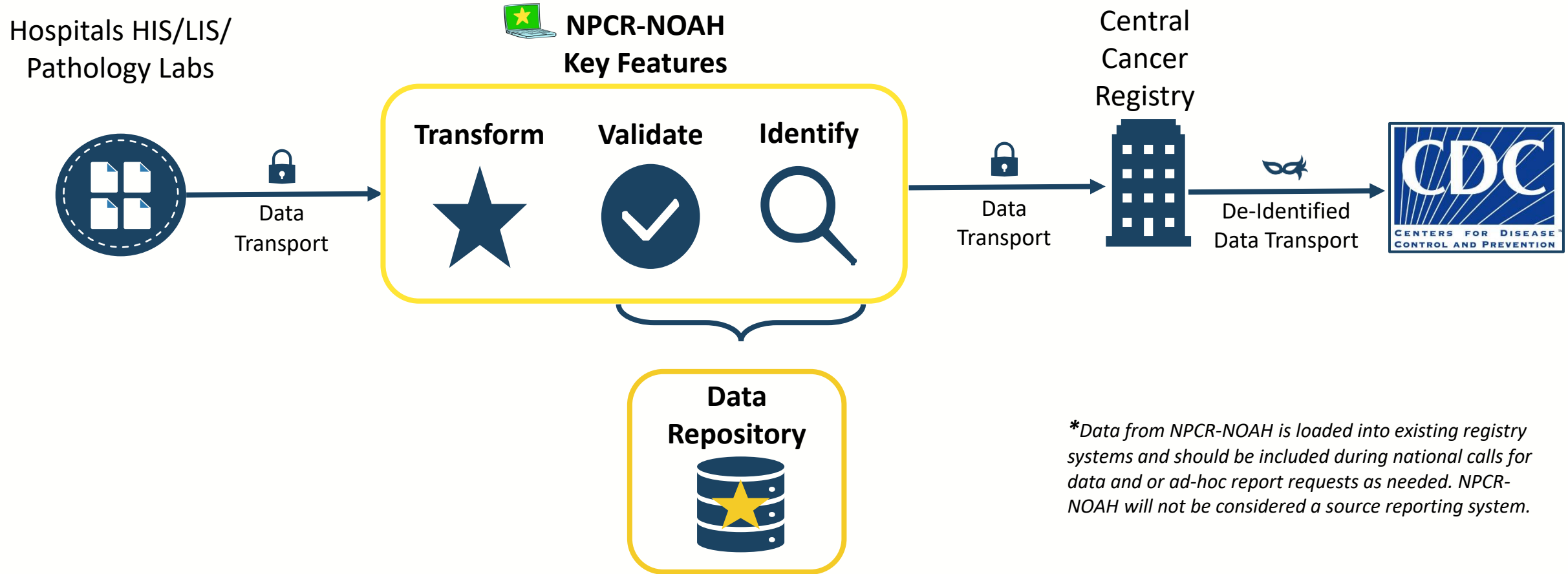
National Program of Cancer Registries National Oncology rapid Ascertainment Hub (NPCR-NOAH)

System Features

- ★ Centralized cloud-based informatics system
- ★ Secure
 - ★ Compliant with HIPAA Security and Privacy rules
 - ★ Meets FedRAMP NIST 800-53
 - ★ Encrypted data
- ★ Scalable and Flexible Architecture
- ★ Built-in data collection and processing features
 - ★ Text-based case finding model
 - ★ Automated data validation



NPCR-NOAH Solution Architecture Framework



**Data from NPCR-NOAH is loaded into existing registry systems and should be included during national calls for data and or ad-hoc report requests as needed. NPCR-NOAH will not be considered a source reporting system.*

NPCR-NOAH Implementation Update

As of August 2022

- ★ Received Authority to Operate (ATO) from the CDC
- ★ Upgraded to a Big Data Platform
- ★ Reviewed approaches to Natural Language Processing (NLP)
- ★ Preparing for pilot production release

CDC DMI

NPCR-NOAH fits within the Big Picture

- CDC-wide effort to modernize core data and surveillance infrastructure across the federal and state public health landscape.
- Goal: Move from siloed and brittle public health data systems to connected, resilient, adaptable, and sustainable systems.
- More than technology:
 - Right people, Right processes, Right policies
 - Real-time high-quality information

A 'building block' project

Shared resource within CDC larger DMI effort

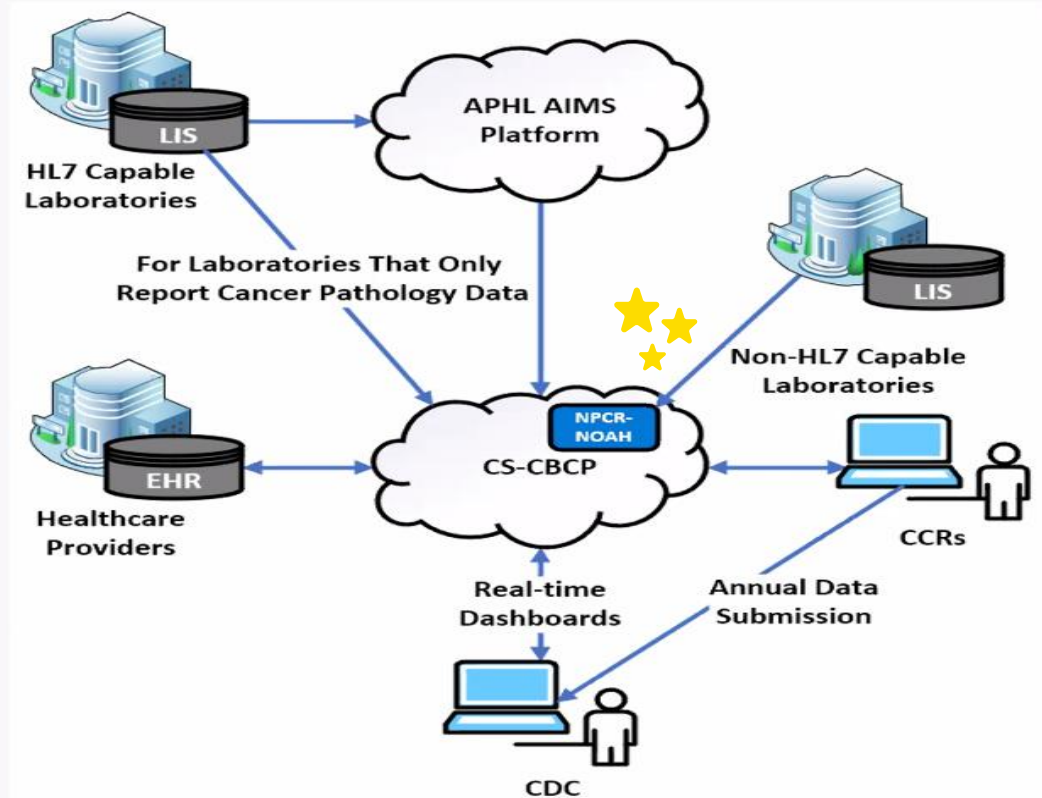
- Promote consistency
- Avoid redundancy
- Economy of scale

<https://www.cdc.gov/surveillance/data-modernization>

NPCR National Oncology rapid Ascertainment Hub (NPCR-NOAH)

- ★ Fits with Cancer Surveillance
Cloud-Based Computing
Platform (CS-CBCP)
- ★ Aligns with CDC/NPCR Data
Modernization Initiative
(DMI) Strategy

Tying the first phase of the CS-CBCP together



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Provide timely data

Improve understanding and lives of children, adolescent, and young adults diagnosed with cancer



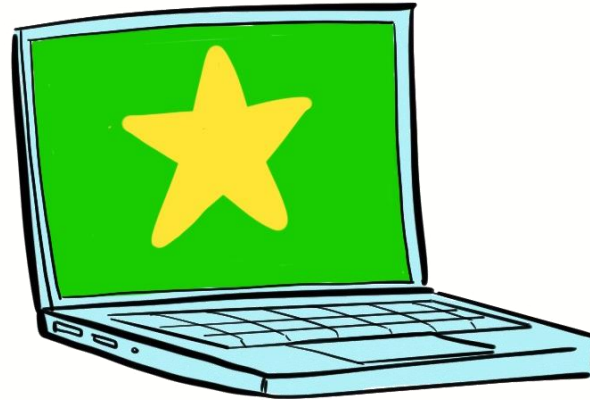
- ★ Provide data to researchers, clinical teams, and public health planners for approved projects
- ★ Enable states to submit deidentified data to CDC
- ★ Sharing childhood cancer data with the National Cancer Institute's National Childhood Cancer Registry (NCCR)

CDC STAR Project Summary



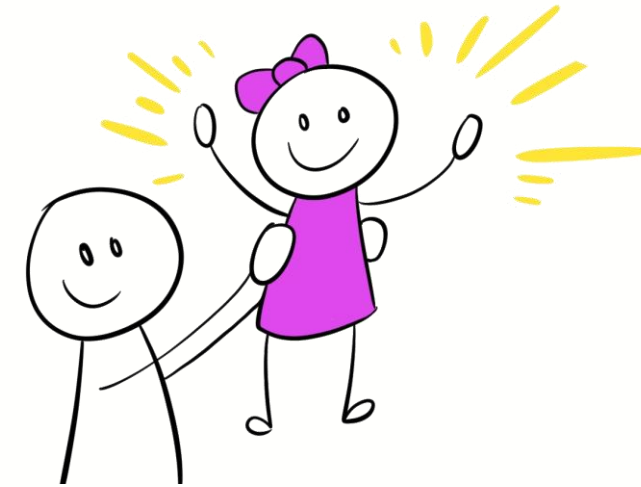
- Process -

Rapid Case Reporting



- Technology - NPCR-NOAH

National Program of Cancer Registries
National Oncology rapid Ascertainment Hub



- People -

Registrars
Children, Adolescents
Young Adults

Thank you!

Go to the official federal source of cancer prevention information:

www.cdc.gov/cancer

Acknowledgments:

Georgia

Ohio

Nebraska

Rhode Island

Texas

Tanaq Support Services

STAR Advisory Group members

Laboratories



Childhood Cancer
STAR ACT

Division of Cancer Prevention and Control

Reliable. Trusted. Scientific.