



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

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Current Landscape of Reporting



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

106 STAT. 3372 PUBLIC LAW 102-515-OCT. 24, 1992

> Public Law 102-515 102d Congress

> > An Act

Oct. 24, 1992 [S. 3312]

Cancer

Registries Amendment Act.

Diseases. Health and

health care

42 USC 280e

Entitled the "Cancer Registries Amendment Act".

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, SECTION 1. SHORT TITLE.

This Act may be cited as the "Cancer Registries Amendment

Act*. SEC. 2. FINDINGS AND PURPOSE

42 USC 201 not 42 USC 280e (a) FINDINGS .- Congress finds that-

(1) cancer control efforts, including prevention and early detection, are best addressed locally by State health departments that can identify unique needs; (2) cancer control programs and existing statewide population-based cancer registries have identified cancer incidence and cancer mortality rates that indicate the burden of cancer for Americans is substantial and varies widely by geographic location and by ethnicity:

(3) statewide cancer incidence and cancer mortality data can be used to identify cancer trends, patterns, and variation for directing cancer control intervention

(4) the American Association of Central Cancer Registries (AACCR) cites that of the 50 States, approximately 38 have established cancer registries, many are not statewide and 10 have no cancer registry; and

(5) AACCR also cites that of the 50 States, 39 collect data on less than 100 percent of their population, and less than half have adequate resources for insuring minimum standards for quality and for completeness of case information.

(b) PURPOSE .- It is the purpose of this Act to establish a national program of cancer registries.

SEC. 3. NATIONAL PROGRAM OF CANCER REGISTRIES Title III of the Public Health Service Act (42 U.S.C. 241 et seg.)

is amended by adding at the end the following new part: *PART M-NATIONAL PROGRAM OF CANCER REGISTRIES

"SEC. 399H. NATIONAL PROGRAM OF CANCER REGISTRIES.

"(a) IN GENERAL .- The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States, or may make grants or enter into contracts with academic or nonprofit organizations designated by the State to operate the State's cancer registry in lieu of making a grant directly to the State, to support the operation of population-based, statewide cancer registries in order to collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin) data concerning.

69,139-01, 92 (515)

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"

Division of Cancer Prevention and Control

-3



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





NPCR-NOAH <u>National Program of Cancer Registries</u> <u>National Oncology rapid Ascertainment Hub</u>

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

All reporting facilities that diagnose or treat patients aged 0-29 Who Partial abstracts / Suspense List • Patients aged 0-29 What • Minimum data set • Diagnosed on or after Jan 1, 2020 **Routine submissions** When Earlier than 6 months Submission to Central Cancer Registry (CCR) Where ٠ Processes to be defined with CCR How

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

Timely Data on Childhood Cancer



Laboratories Reporting Sources

State-based Central Cancer Registries

NPCR-NOAH <u>National Program of Cancer Registries</u> <u>National Oncology rapid Ascertainment Hub</u>



<u>National Oncology rapid Ascertainment Hub</u>



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 <u>National Oncology rapid A</u>scertainment <u>H</u>ub (NPCR-NOAH)

System Features

- \star 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
 - \star Automated data validation



NPCR-NOAH Solution Architecture Framework



NPCR-NOAH Implementation Update As of August 2022

*****Received Authority to Operate (ATO) from the CDC

 \star Upgraded to a Big Data Platform

★Reviewed approaches to Natural Language Processing (NLP)

+ Preparing for pilot production release



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

CDC DMI

NPCR-NOAH fits within the Big Picture

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 <u>National Oncology rapid Ascertainment Hub (NPCR-NOAH)</u>

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

Tying the first phase of the CS-CBCP together



CDC STAR Project





Timely Data on Childhood Cancer



Laboratories Reporting Sources

State-based Central Cancer Registries

NPCR-NOAH <u>National Program of Cancer Registries</u> <u>National Oncology rapid Ascertainment Hub</u>

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



Rapid Case Reporting



- **Technology** - NPCR-NOAH

<u>National Program of Cancer Registries</u> <u>National Oncology rapid Ascertainment Hub</u>



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



Division of Cancer Prevention and Control

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.