Real-time Registry Reporting: Pathway to Better Cancer Prevention and Treatment

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NSoLEM Stakeholder Forum
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“Data is moving slower than the disease…”

“The nation’s public health data systems are antiquated and in dire need of security upgrades - paper records, phone calls, spreadsheets and faxes requiring manual data entry are still are in widespread use and have significant consequences including delayed detection and response, lost time, missed opportunities and lost lives.”

Testimony of Janet Hamilton, Director of Science and Policy at CSTE, speaks at Public Witness Day, April 9, 2019
Labor, Health and Human Services, Education, and Related Agencies (116th Congress)

Surveillance is a Foundational Data Activity in Public Health

Timely, high quality, actionable data is central to fulfilling the 10 essential functions of public health.

NPCR & SEER – USCS Public Use Databases

- Incidence and demographic data for all new cancer cases
- 100% population coverage for the U.S. and Puerto Rico

www.cdc.gov/cancer/public-use

CDC's National Program of Cancer Registries

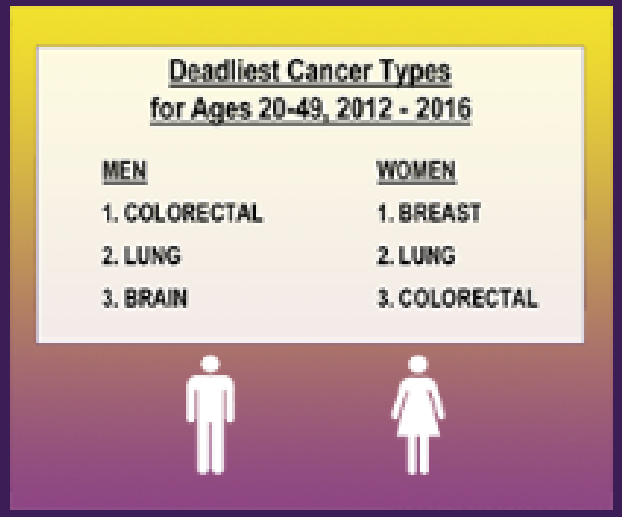
1.66 million	New cancer cases each year
200+ data items for each case	Cancer site and histology Patient demographics Stage at diagnosis First course of treatment

Knowledge Transfer

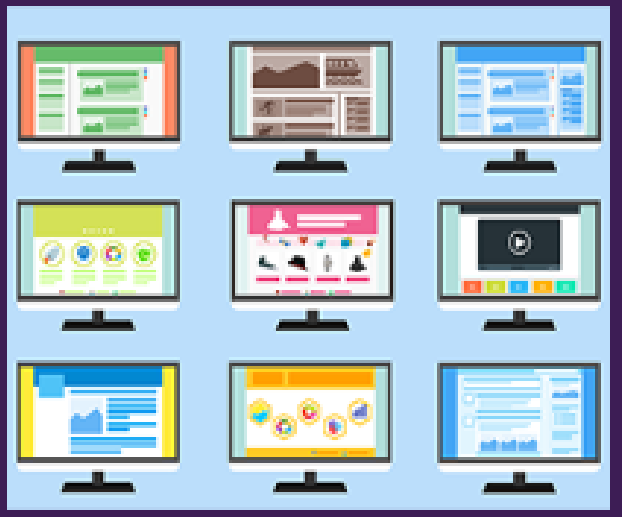
Annual Report to the Nation on the Status of Cancer

Overall Cancer Statistics

Special Topic: Cancer Among Adults Ages 20–49



Shareable Resources



The Challenge

1

Data is at least 24 months old

2

States struggle to meet data quality standards

3

Effort is duplicated per state

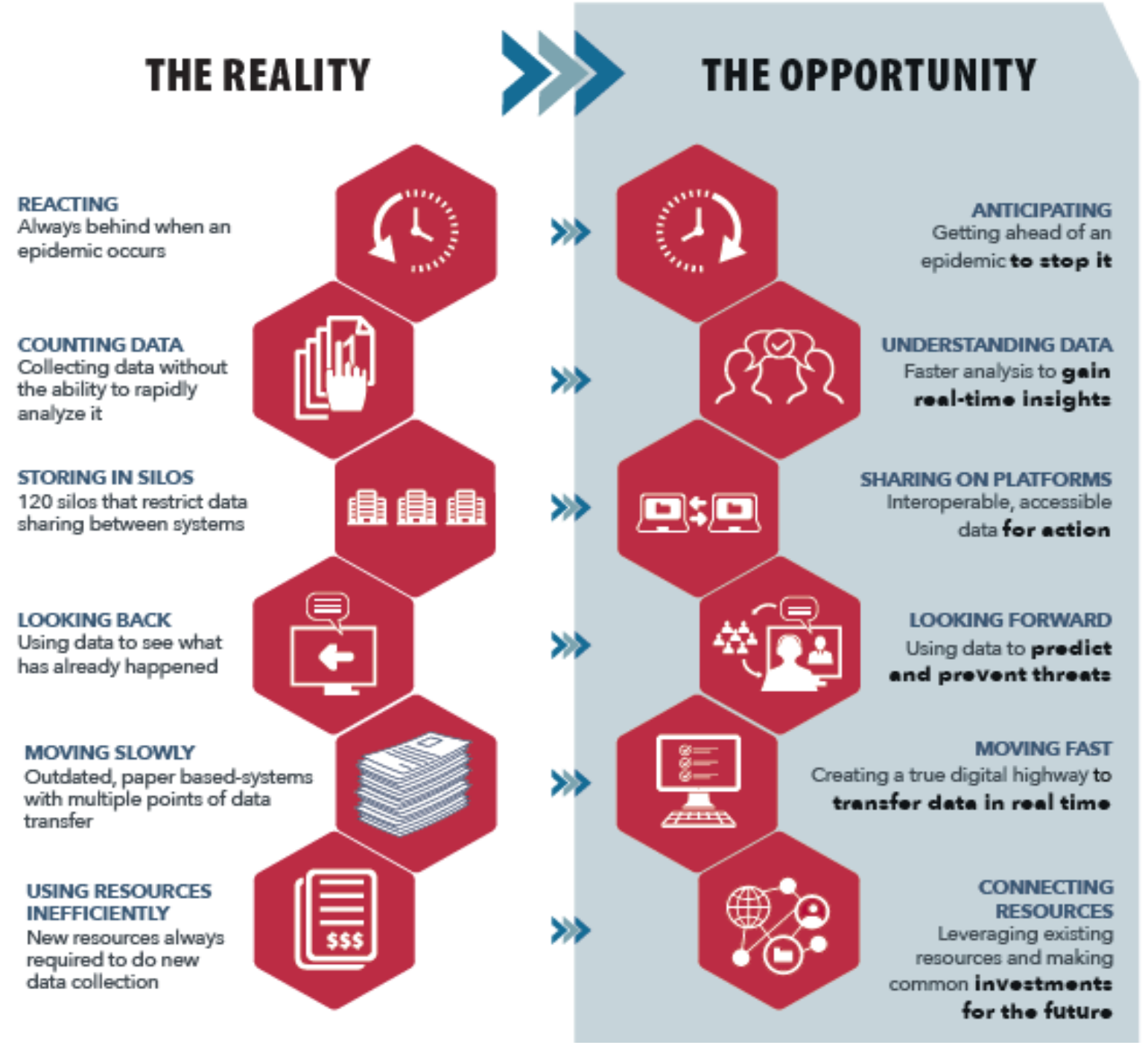
4

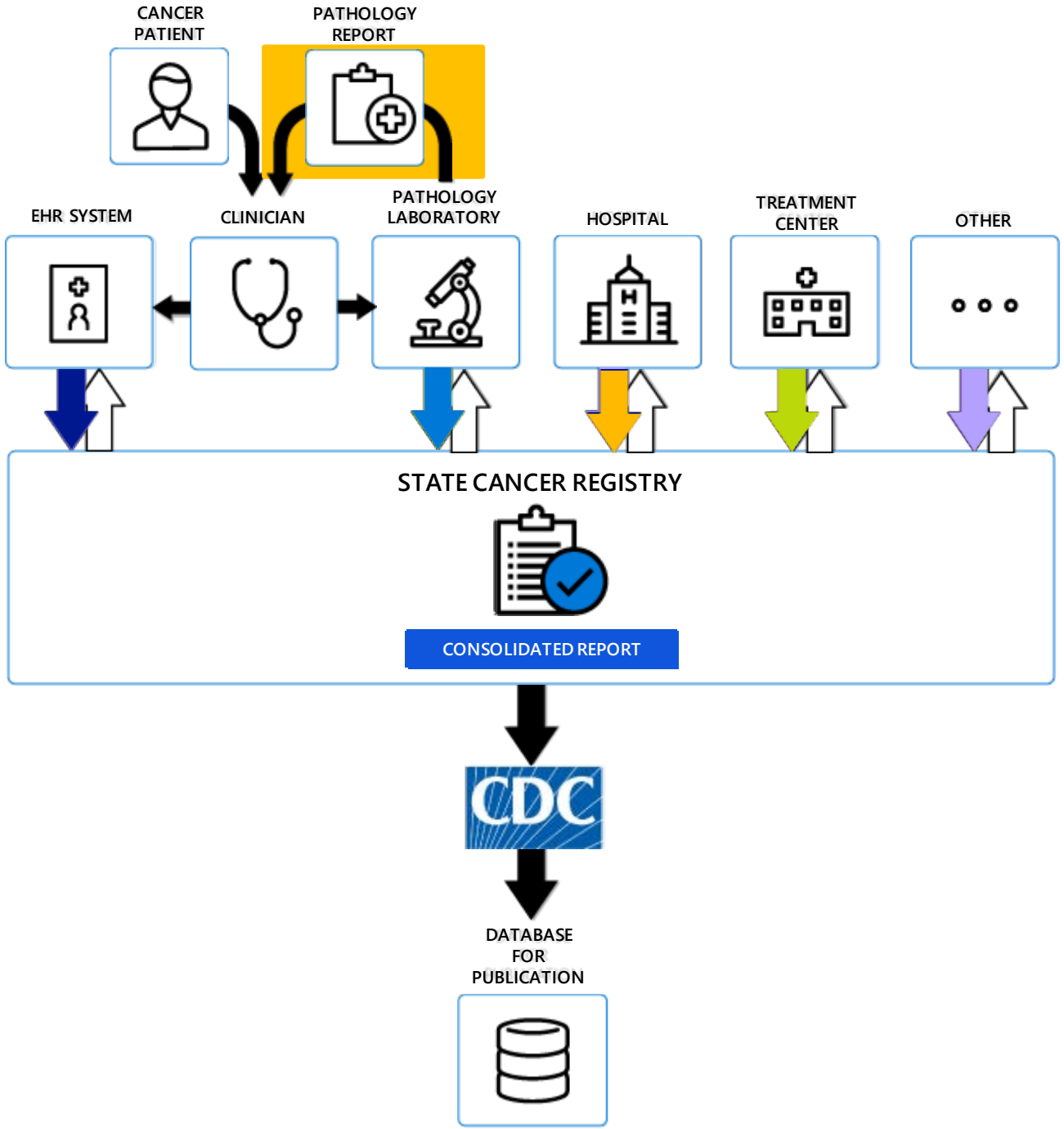
Reporting is labor-intensive and costly

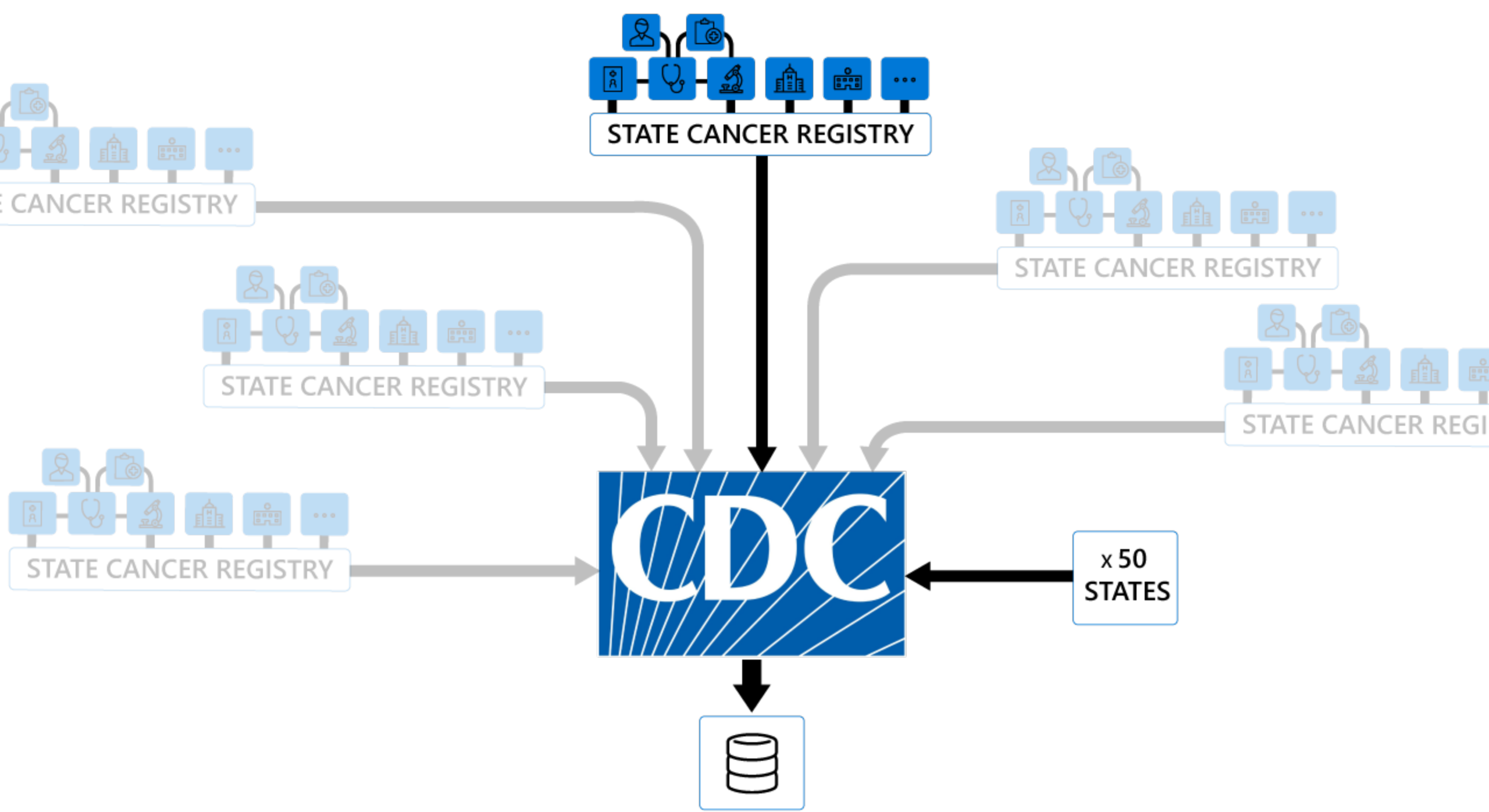
The New World of Public Health Data

Timely, Accurate, Accessible…

CDC is developing world-class data and analytics to transform today's reality and meet new opportunities for lifesaving, prevention, and response.




CANCER PATIENT
PATHOLOGY REPORT
EHR SYSTEM
CLINICIAN
PATHOLOGY LABORATORY
HOSPITAL
TREATMENT CENTER
OTHER
STATE CANCER REGISTRY
CONSOLIDATED REPORT
CDC
DATABASE FOR PUBLICATION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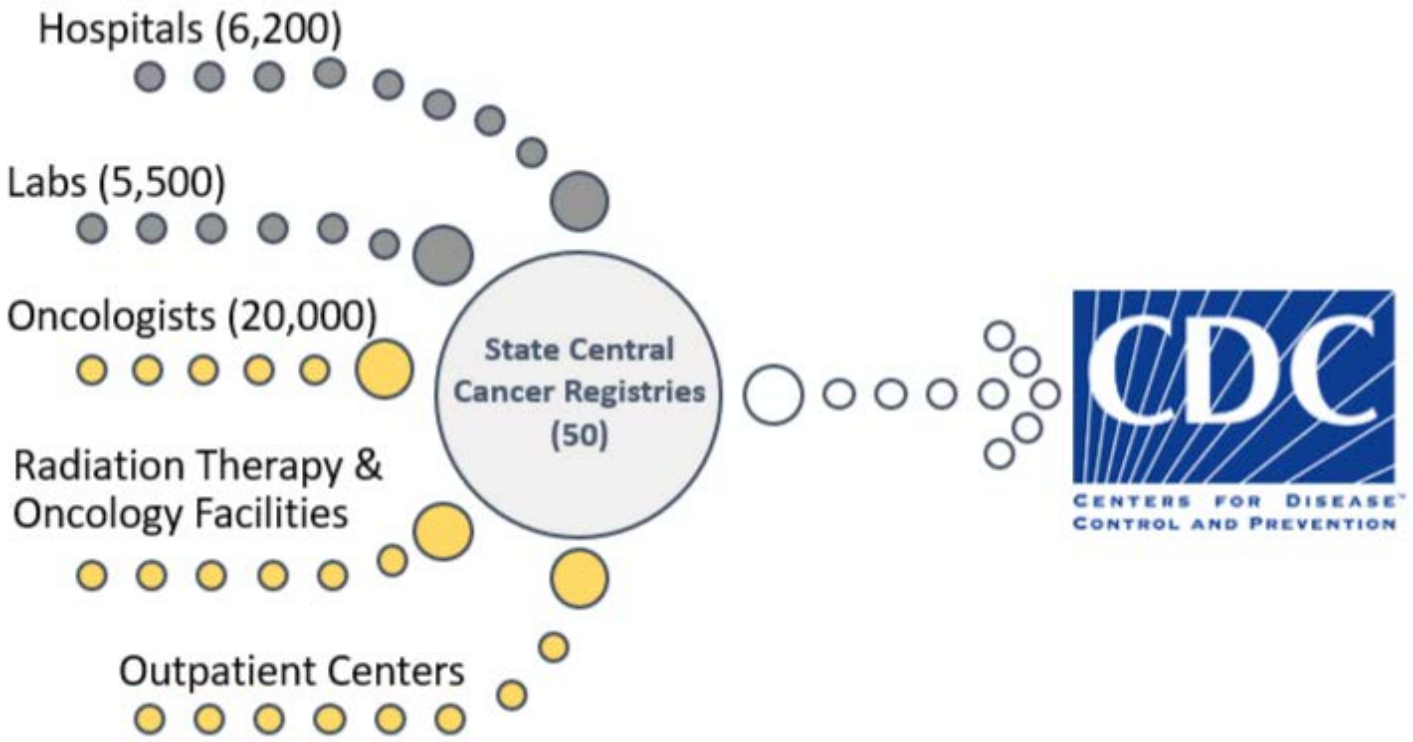
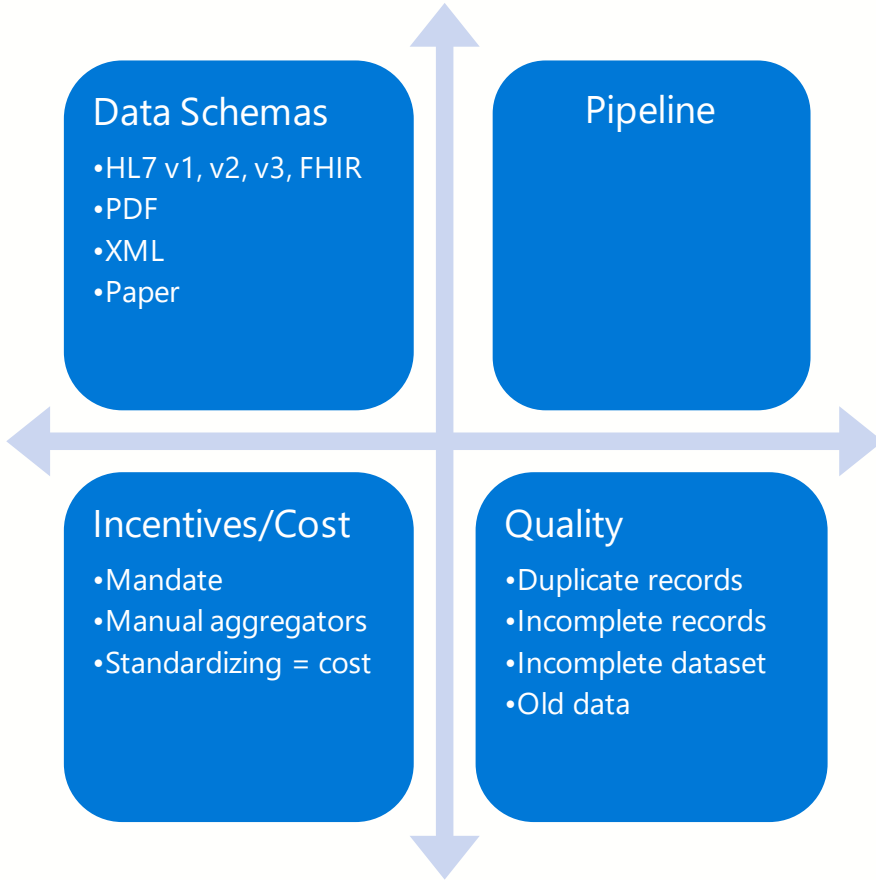
Data Volume, Complexity and Veracity

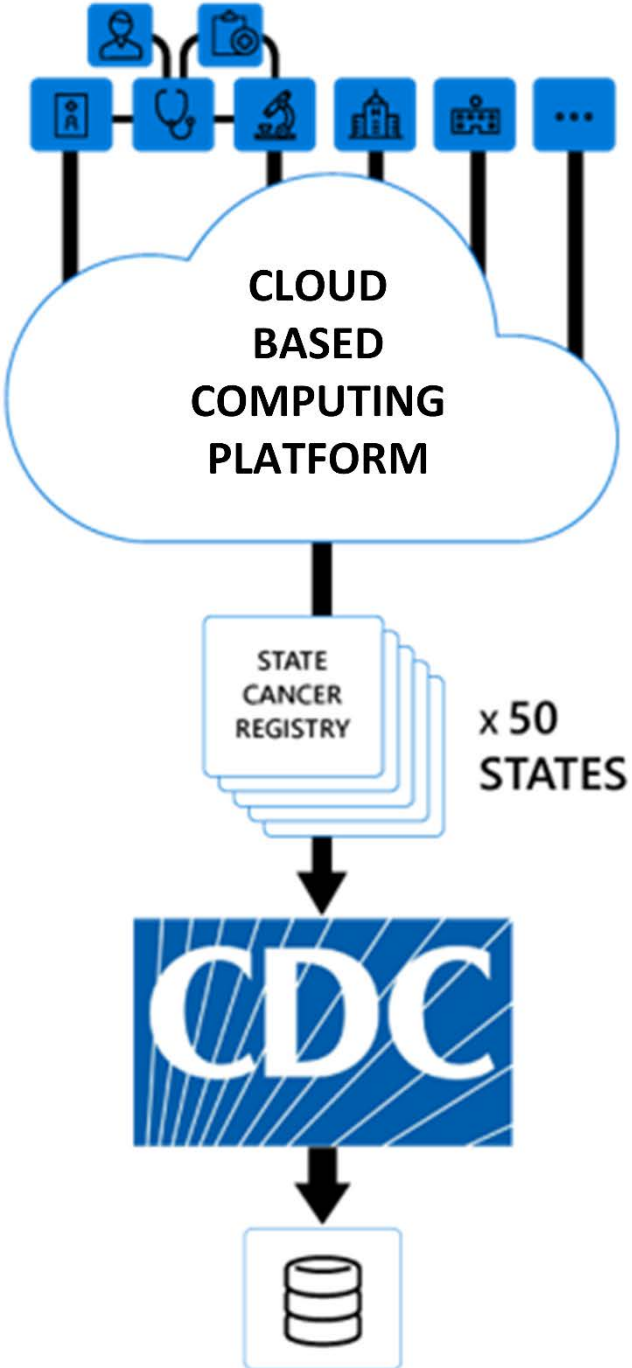




Accelerating Progress in Cancer Control

Public Access and Data Sharing

1. Start with the cloud
2. Automate record creation *where cancer is first detected*
3. Automate follow-back
4. Standardize interfaces with facilities and vendors
5. Base it on an open standard (FHIR)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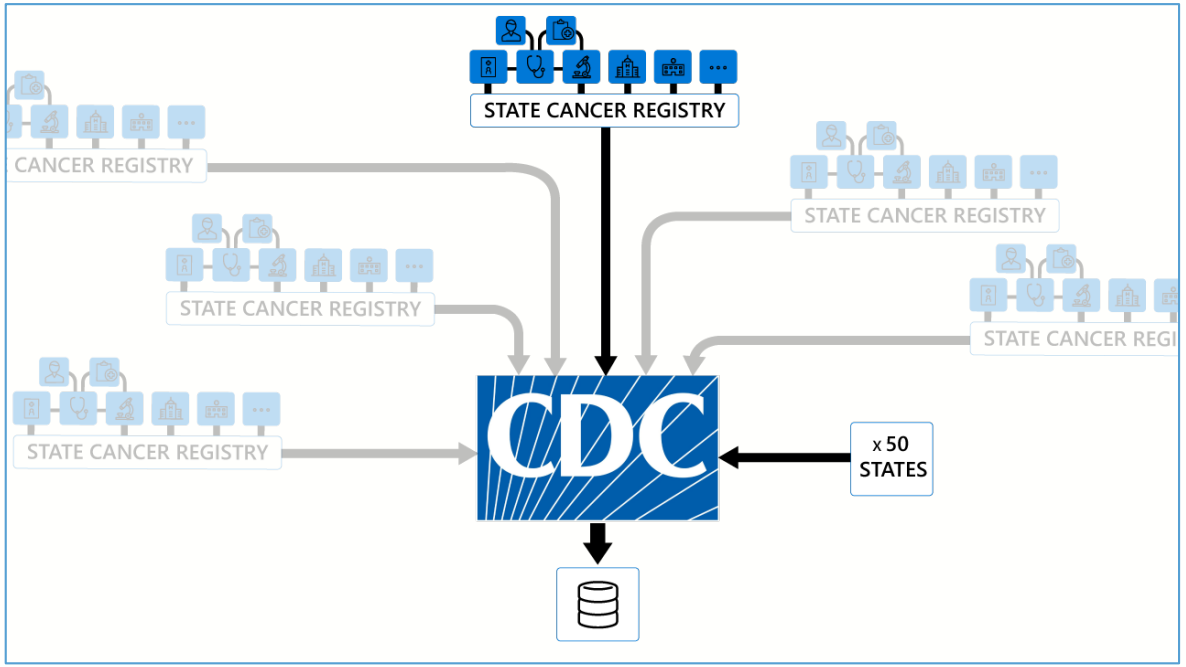
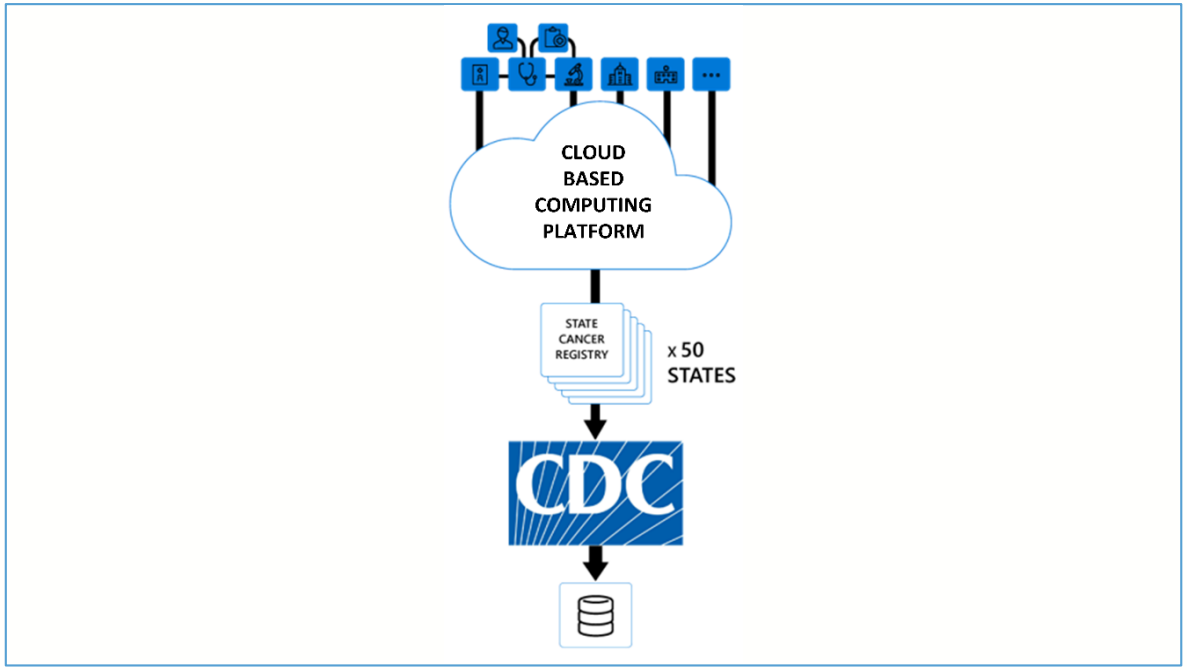
Cancer Surveillance: Current vs Future





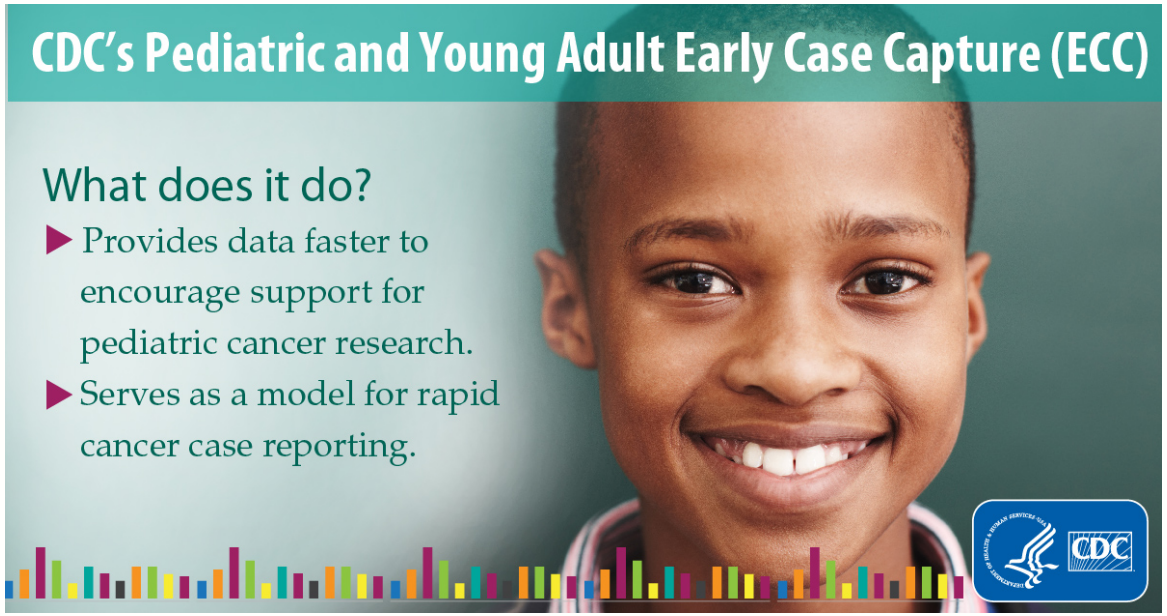
Early Pediatric and Young Adult Case Capture

Funded States (2014-2019)

- KY, LA, MN, NE, NY, RI, WI

Goals

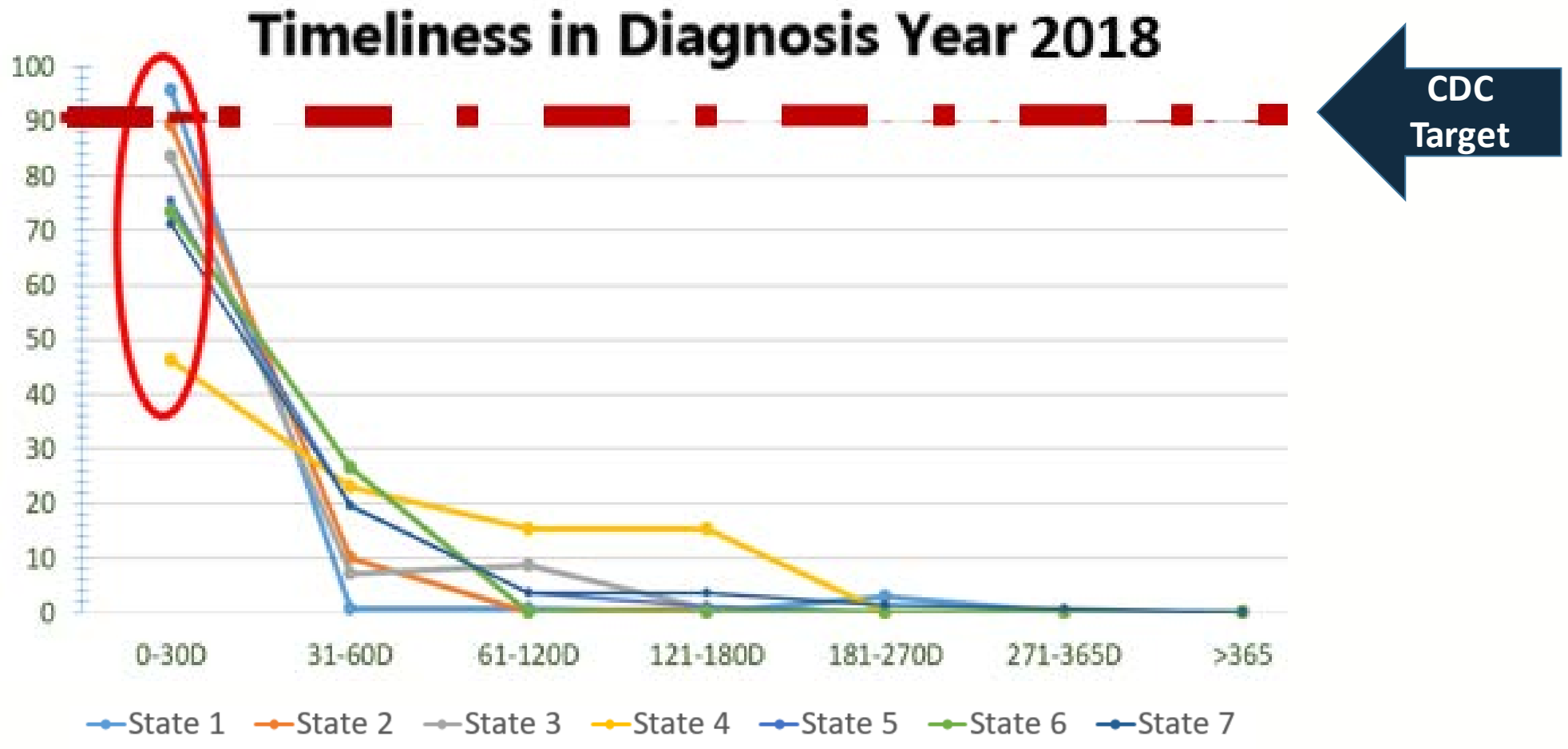
- Rapid electronic reporting (30 days)
- Expand reporting relationships with facilities
- Monitor data quality, completeness, and timeliness
- Increase availability of pediatric data



Source: cdc.gov/cancer/npcr/early-case-capture.htm

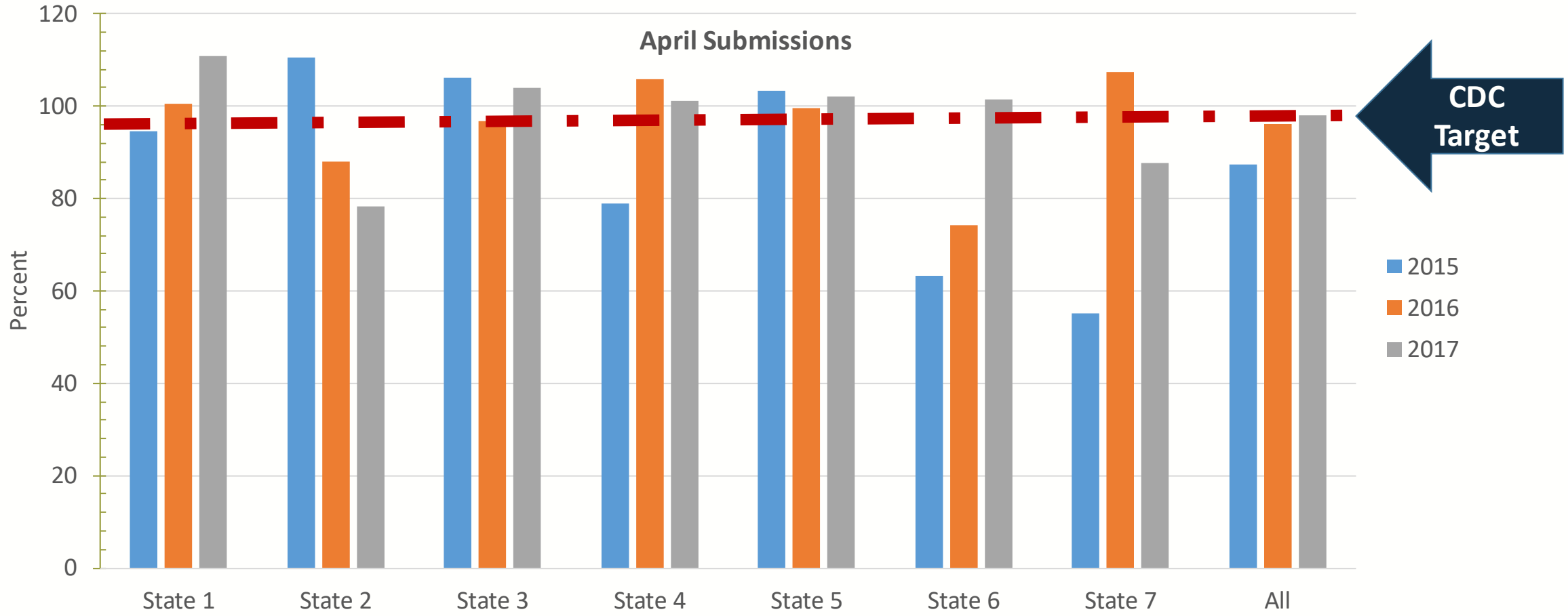
Data Reporting Efficiency in the Real World

Average case reporting skyrockets from 40% in 2014 to over 80% percent in 2018

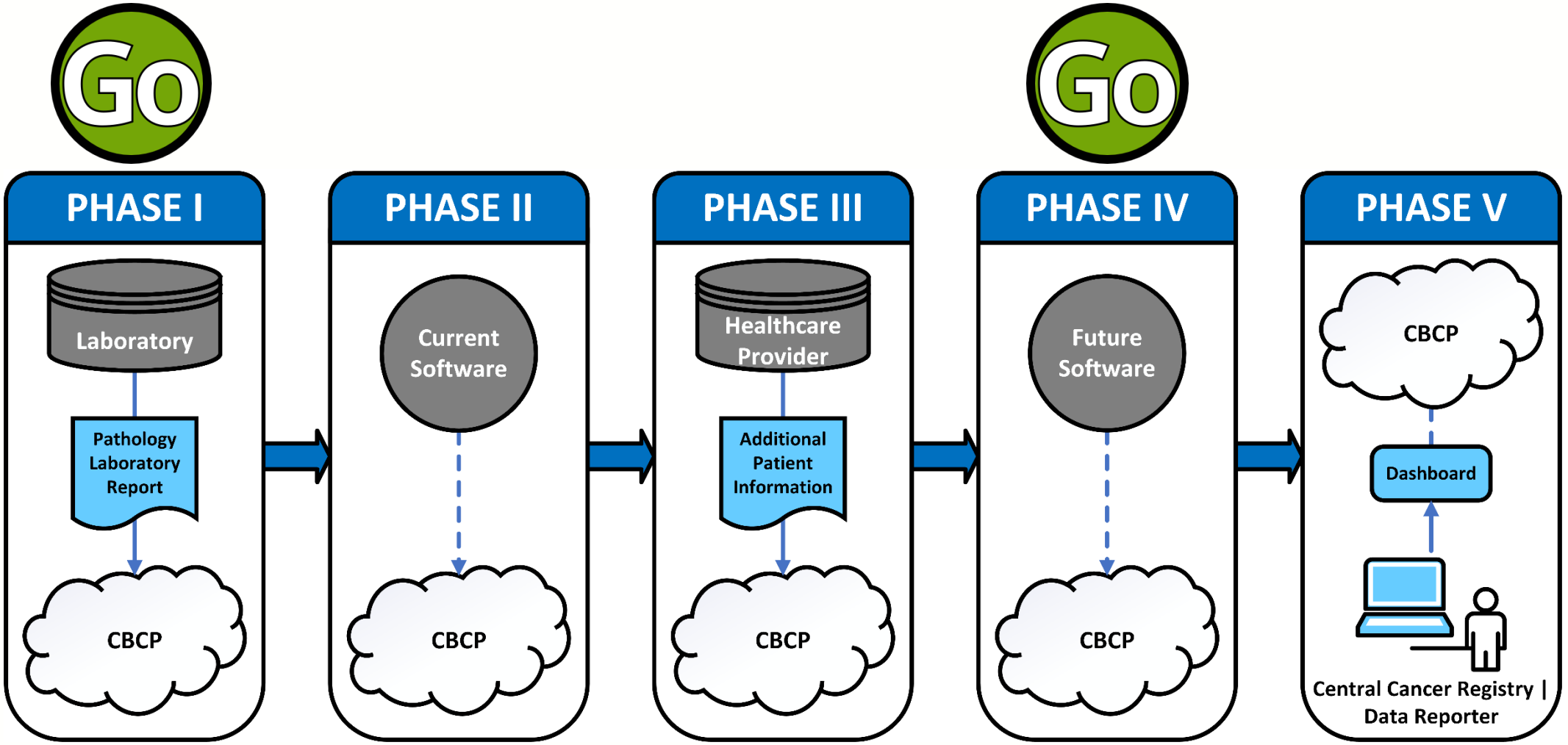


Quality not a trade-off for Speed

CDC reaches its target of having 95 percent of all reports submitted with complete information within 12-months.



Cloud-Based Computing Platform Implementation

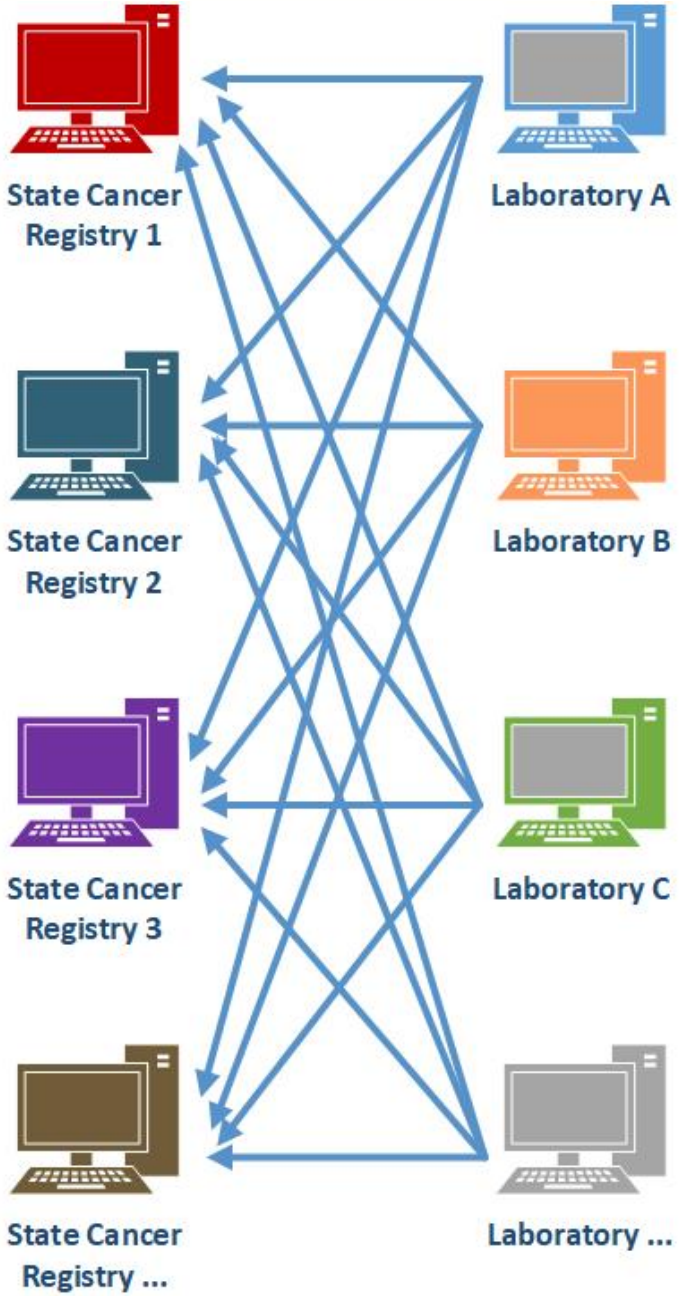


Pathology Reporting Quality and Efficiency

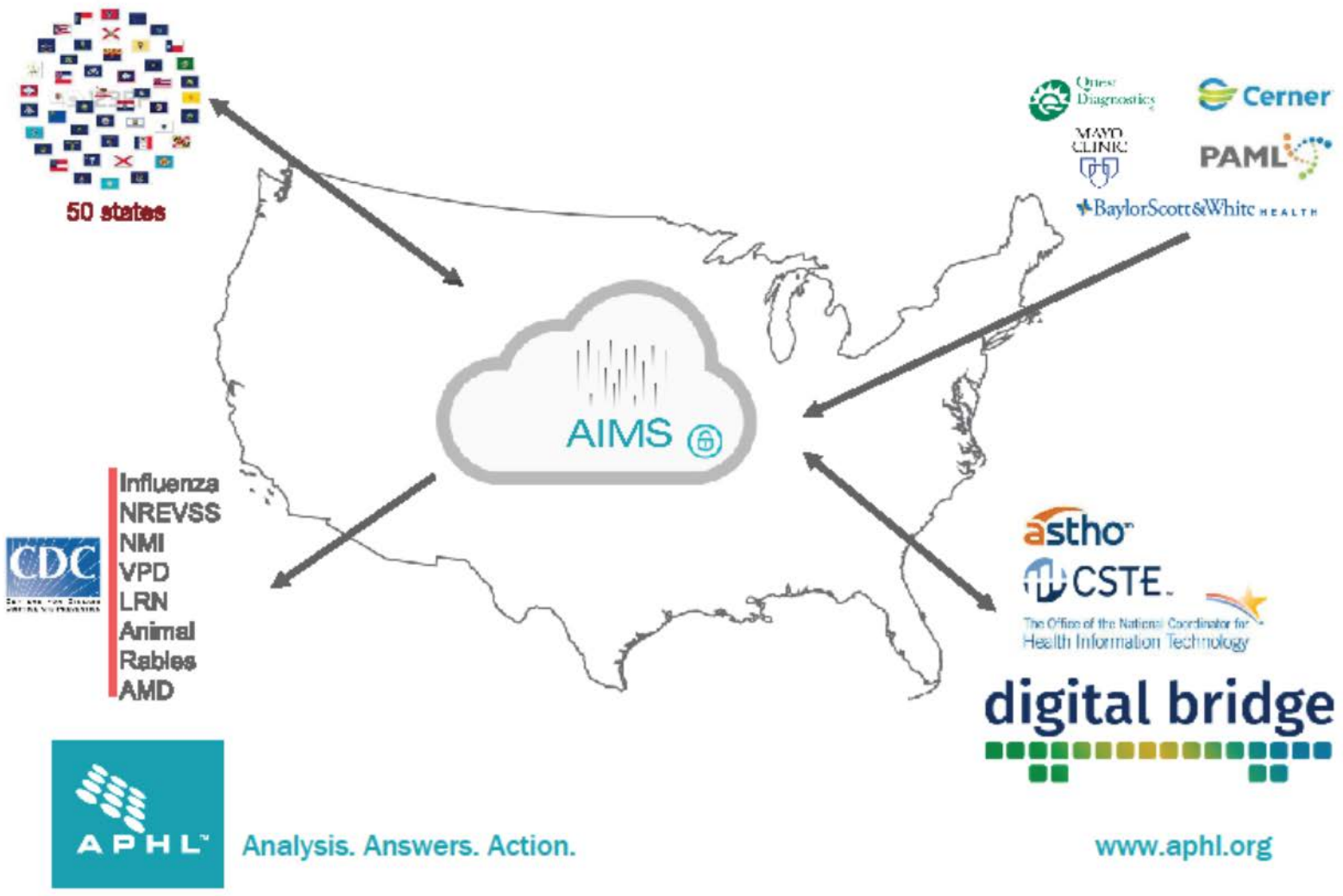
Electronic Pathology reporting Pilot

57 participating national/regional laboratories

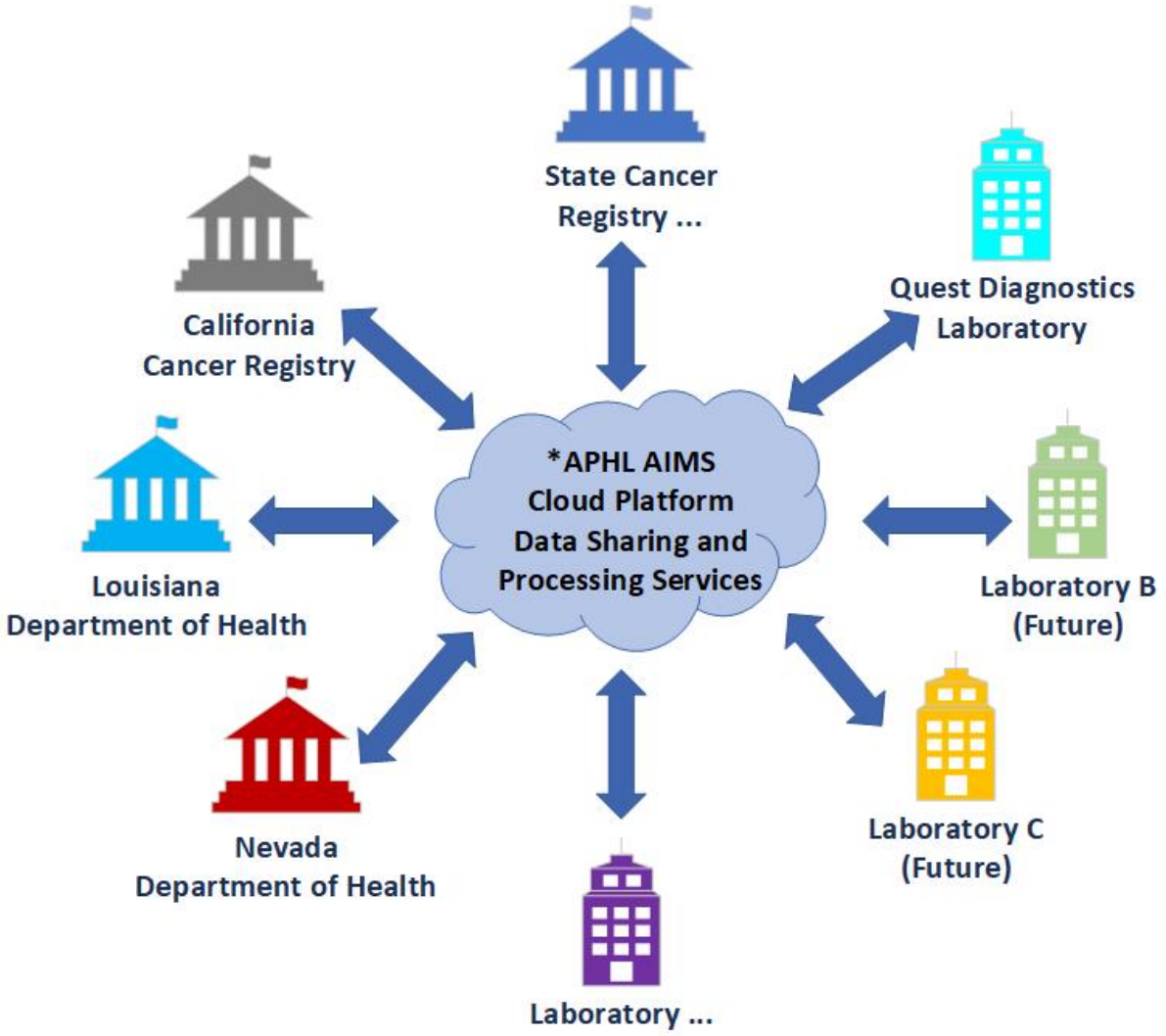
- Direct standardized reporting to state cancer registries
- Establishing ePath standards and secure connectivity a resource-intensive process



A National Resource for Interoperability



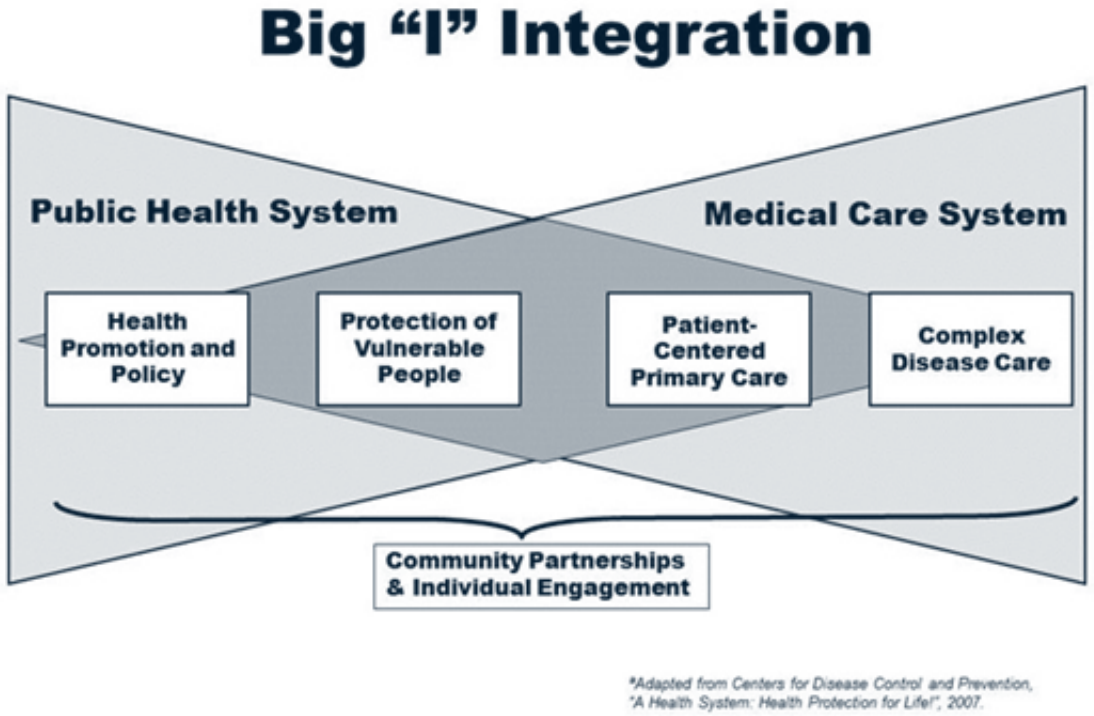
Leveraging Existing Infrastructure



*APHL AIMS: Association of Public Health Laboratories Informatics Messaging Services

- **California**: Direct node on APHL AIMS Platform
- **Louisiana**: Using existing Dept of Health AIMS portal used to receive infectious disease and HIV data, then automated secure routing of data to cancer registry
- **Nevada**: Using existing Dept of Health AIMS portal; cancer registry given access to pull data
- Remaining states and new labs implemented after pilot

Enabling Greater Integration Between Health Care and Public Health



*Adapted from Centers for Disease Control and Prevention, "A Health System: Health Protection for Life!", 2007.

> "The flow of important disease-related information between health care and public health will lead to better care and faster, more effective population health interventions"

John Lumpkin, senior vice president, Robert Wood Johnson Foundation

Thank you!

Go to the official federal source of cancer prevention information:

www.cdc.gov/cancer

Cancer Prevention Works

Division of Cancer Prevention and Control

Reliable. Trusted. Scientific.

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.

Scaling High-quality, Rapid Reporting

CDC software enables unprecedented speed and depth in Registry Reporting

Childhood Cancer STAR ACT

- Collection of data for children and young adults ages 0-29
- 10 central cancer registries in 5 years
- Data more readily available for:
  - early intervention
  - clinical trial enrollment