

Childhood Cancer Data Initiative Surveillance Research Program (SRP) National Childhood Cancer Registry

Florida Cancer Data System (FCDS) Annual Conference

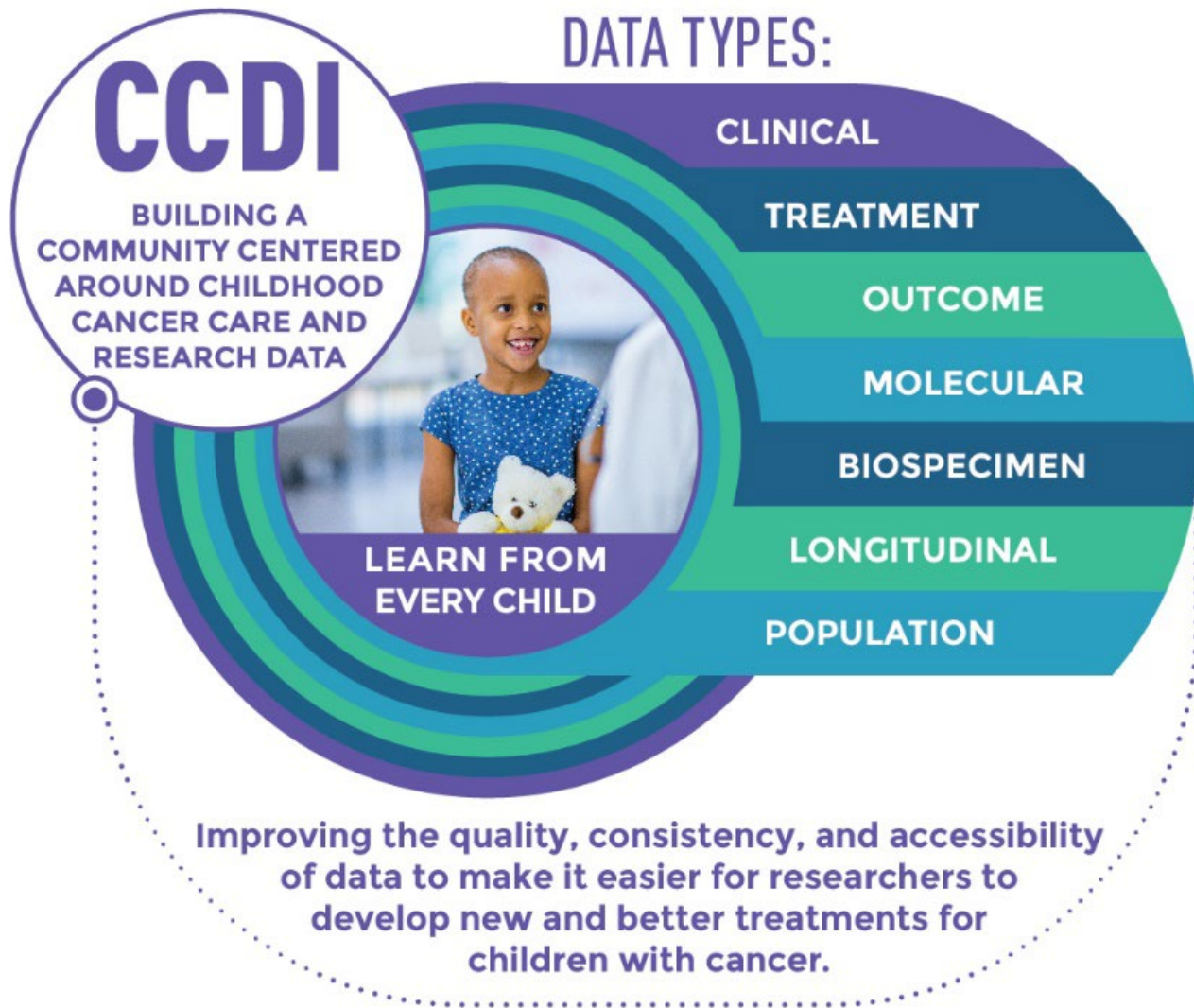
August 25, 2022



Johanna Goderre, MPH, CSPO
NCCR Technical Lead

Health Data Scientist, Surveillance Research Program

NCI's Childhood Cancer Data Initiative (CCDI)



The goal of the CCDI is to build a **community** of

pediatric cancer researchers, advocates, families, hospitals, and networks

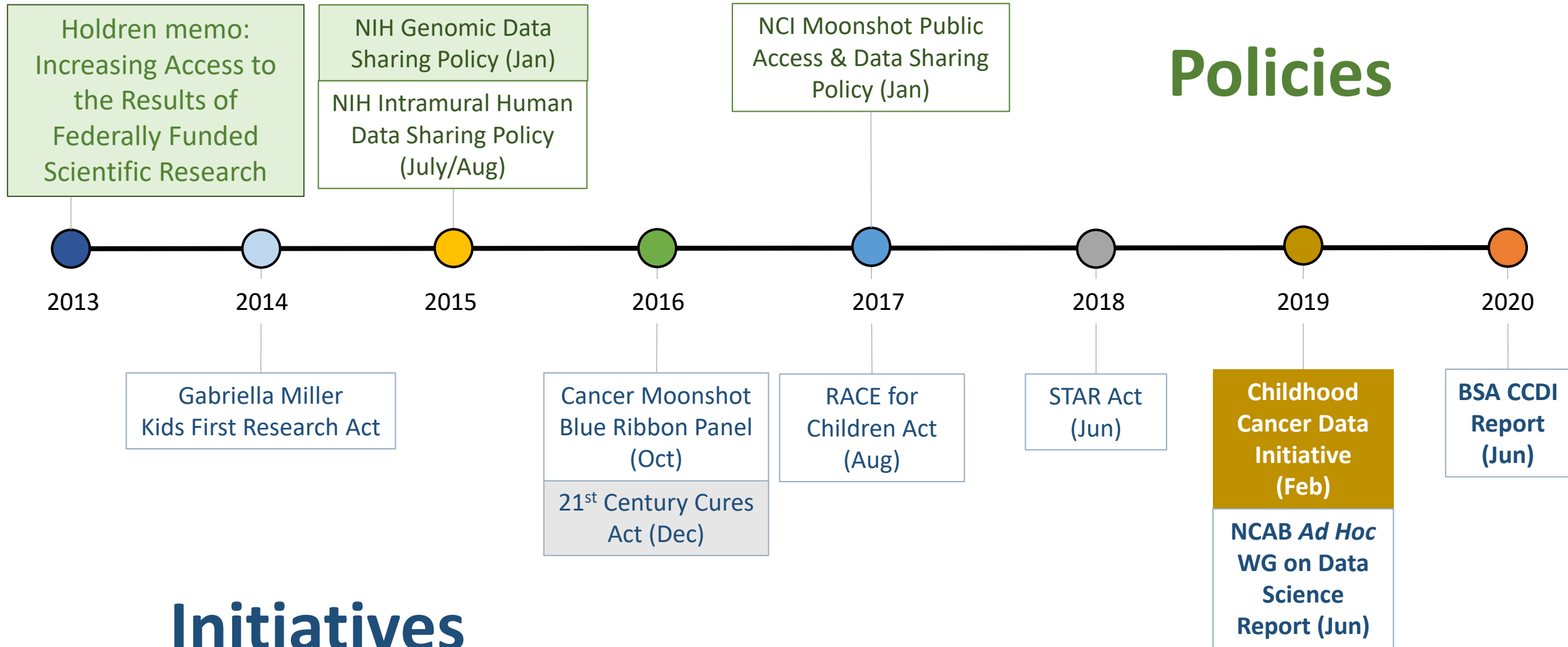
committed to sharing data to improve treatments, quality of life, and survivorship of every child with cancer

\$50 million annual federal investment made in each fiscal year 2020 to 2030

History of Initiatives and Policy Leading up to CCDI

Policies

Initiatives



Childhood Cancer Data Initiative (CCDI) Symposium

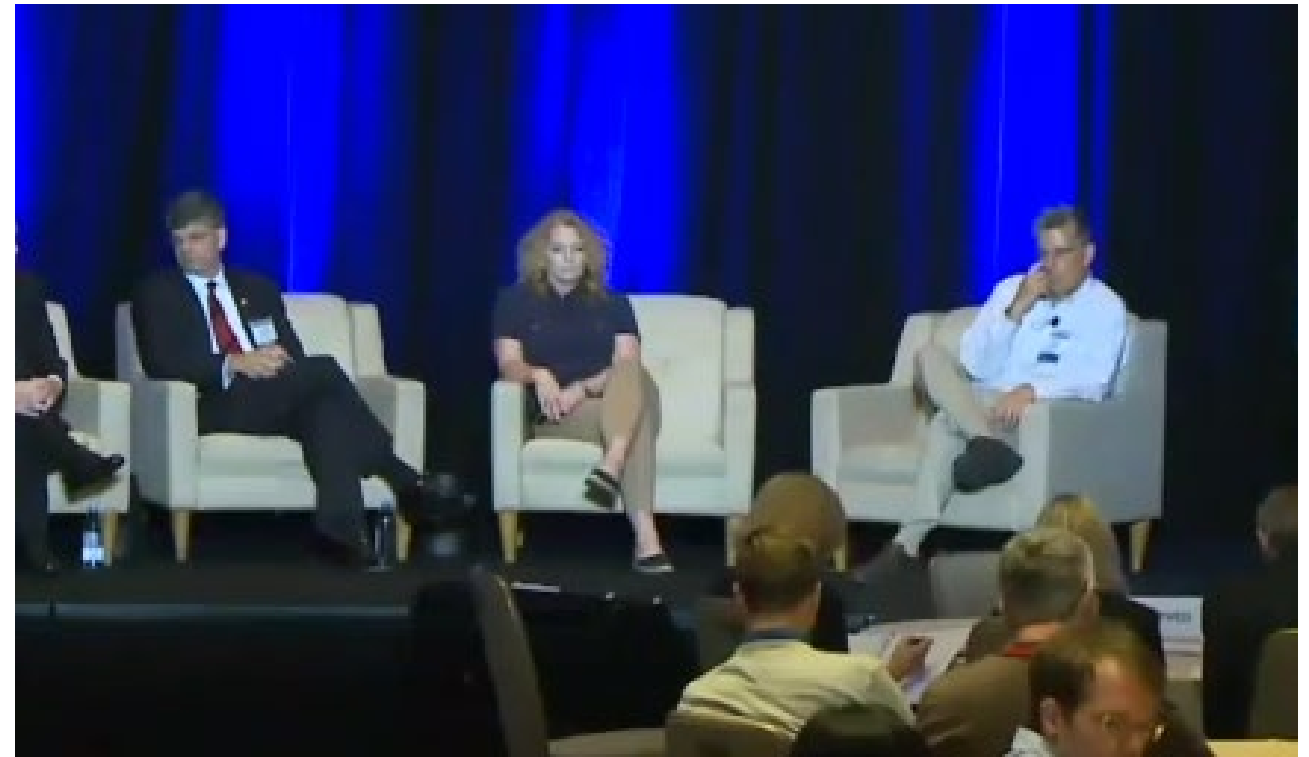
Scientific stakeholders and leaders from academia, government, industry, and advocacy organizations gathered in Washington, DC, July 29–31, 2019, for the NCI Childhood Cancer Data Initiative (CCDI) Symposium—a scientific meeting to gain a common understanding of the current issues and opportunities in childhood cancer research that can be addressed through enhanced data collection and maximum utilization of that data.

<https://www.cancer.gov/research/areas/childhood/childhood-cancer-data-initiative/symposium>

Watch Recordings of the Symposium

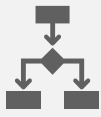
Day 1: Monday, July 29, 5:00 p.m. - 7:30 p.m.

Day 2: Tuesday, July 30, 8:30 a.m. - 12:30 p.m.



June 2020 CCDI Board of Scientific Advisors Working Group Report

24 specific
recommendations



Landscape of Pediatric/AYA Cancer Research Data & Needs Analysis



Types of Data for Collection and Aggregation



Potential Barriers to Progress



Generating New Data



Distinction Between Research & Clinical Data



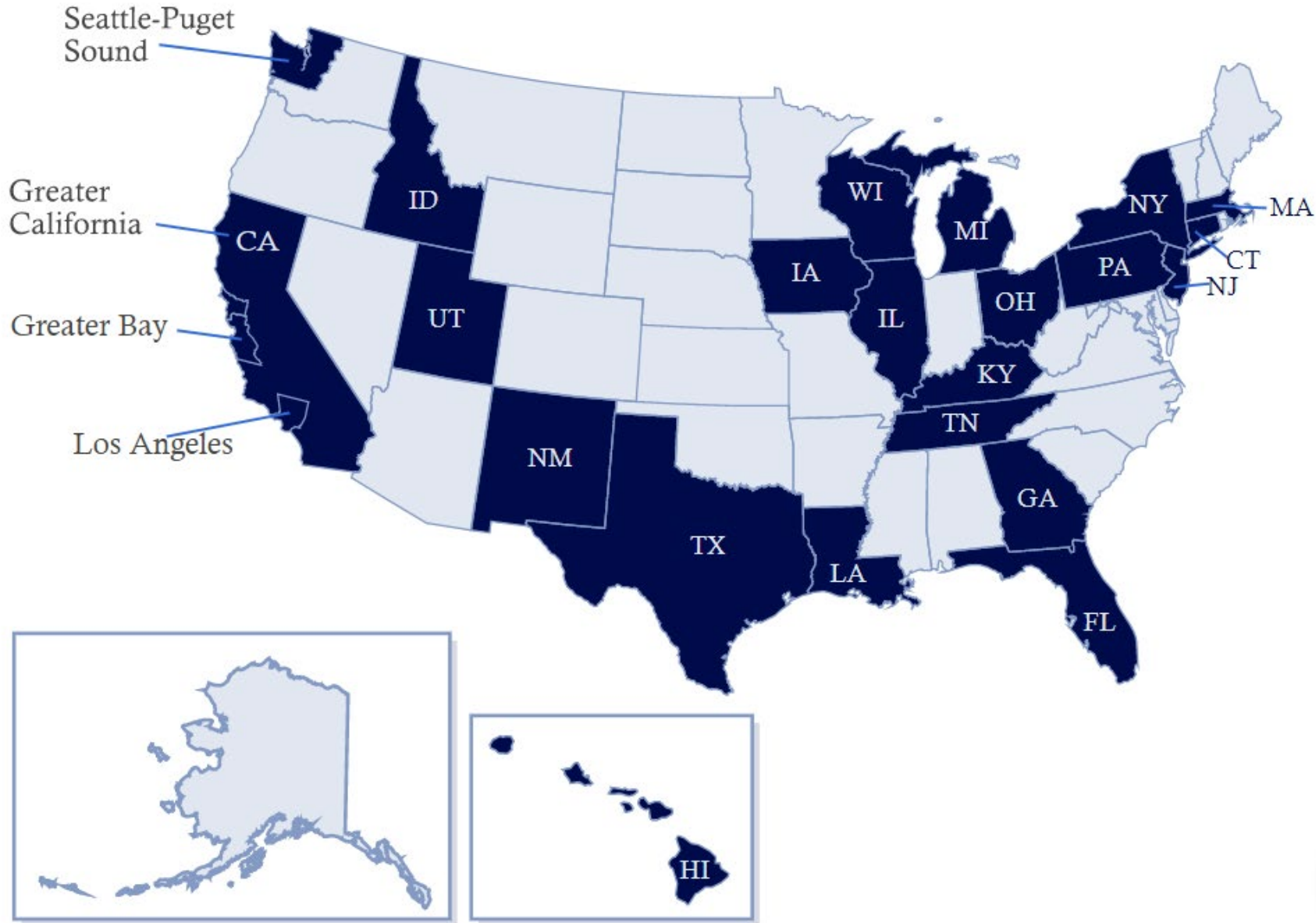
Engaging Diverse Array of Stakeholders for Input



Potential Opportunities for Transformative Discoveries

CCDI --> National
Childhood Cancer Registry
(NCCR)

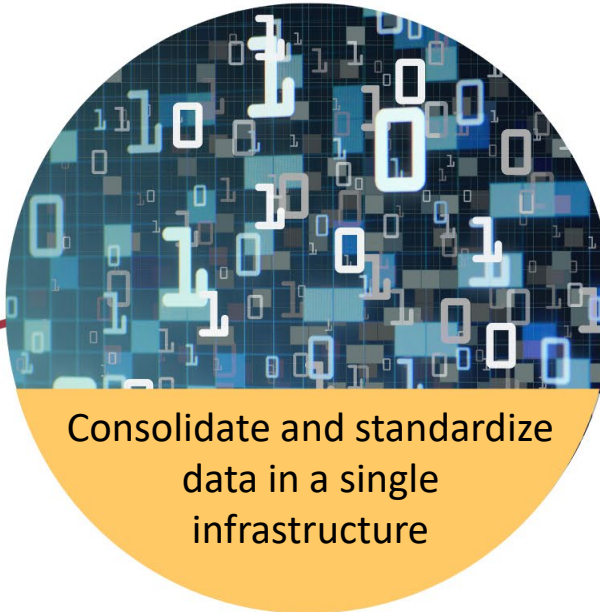
Central Cancer Registries participating in the NCCR



National Childhood Cancer Registry

Approximately 16,000 childhood cancer patients are diagnosed in the United States annually, compared with the 1.8 million new cancer cases among all ages.

Initial Registry Participation = ~70% of US population



Data Domains:

- Longitudinal Treatment, Procedures, Outcomes (including pharmacy data, radiation oncology, claims, radiology, vital status)
- Social Determinants of Health (including financial toxicity, residential history)
- Clinical Trials, Survivorship Studies, Biospecimen or Tissue Location
- Tumor and Germline Molecular Characterization

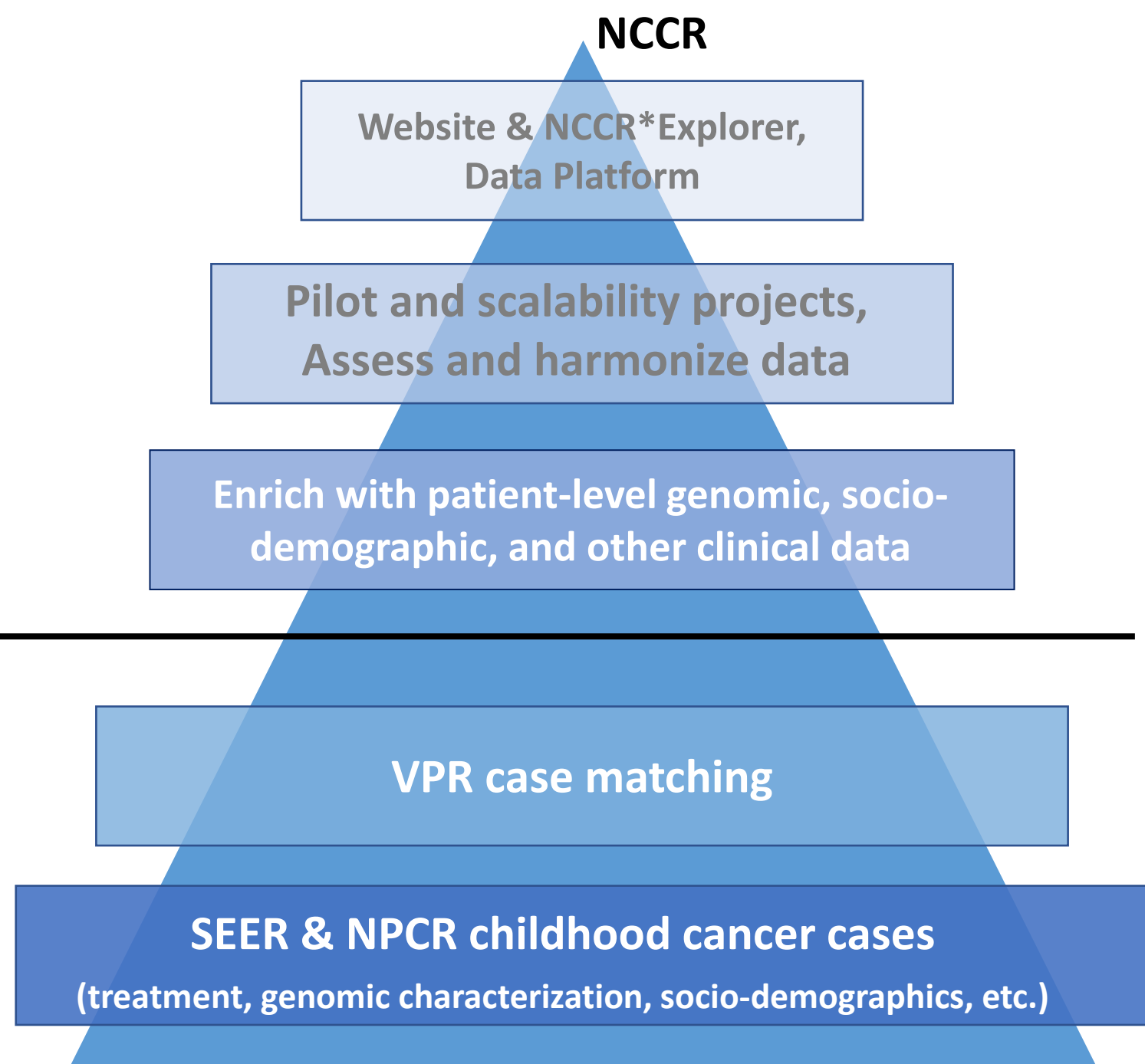
CCDI National Childhood Cancer Registry

- Leverage and link disparate data from multiple sources to create an infrastructure that can better support surveillance and research on childhood cancer
- 24 central cancer registries, including 5 NPCR (MI, PA, TN, OH, FL)
- Core data derived from cancer registries- but extended and expanded to include additional relevant information such as
 - Detailed treatment
 - Genomic characterization
 - Trajectory of care from diagnosis throughout life including
 - Multiple primary cancers
 - Recurrent disease
 - Other relevant factors related to risk and outcome (residential history, SDOH etc.)
- Integrate within modern CCDI federated data ecosystem
- Include data on a broader set of patients than covered in COG facilities
 - Potential disparities in who is seen/treated in COG systems
 - Preliminary data estimating proportion of patients seen at COG facilities in SEER: 65-77% overall

- Communicate progress!
- Pilots like Birth Records, Whole Slide Imaging, Medicaid
- Other efforts to improve data quality and resources with CDC, HemOnc.org, DOE
- Linkages from detailed, non-registry sources like Cancer Centers, COG, Pediatric Proton/Photon Registry

Census of all childhood cancer cases

- NAACCR Virtual Pooled Registry
 - De-duplication & longitudinal matching
 - 9 states in 2022
 - Enable survivorship studies
- High-quality PII/PHI-based matching of individuals across many data sources
- Rich data from SEER registry abstracts (since 1995; expanding to <40 year-olds)





Birth

Cancer
Diagnosis

1995, age 5



Biomarkers



Outcome

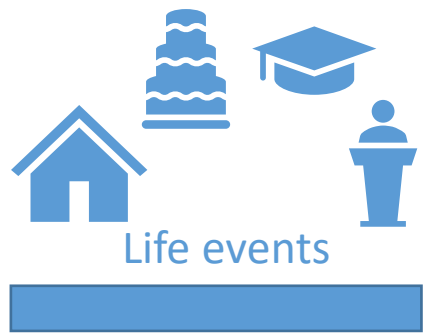
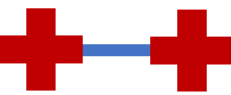


Treatment or Trial

1995-1996

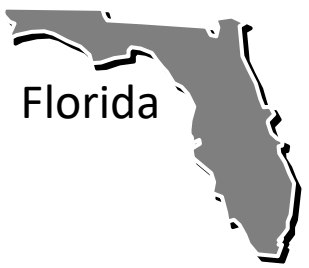


Healthcare
visit



Life events

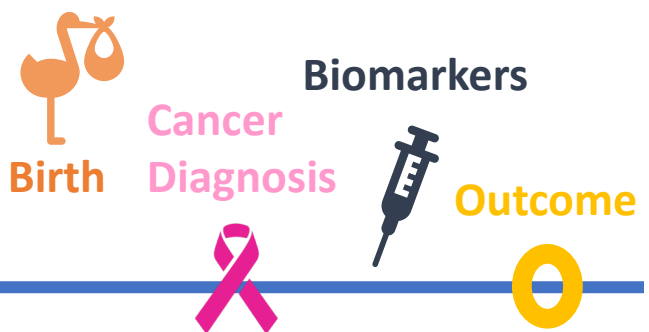
2015, age 20



Cancer
Diagnosis

2021, age 26





1995, age 5





Birth

Cancer
Diagnosis



1995, age 5



Louisiana

Biomarkers



Outcome



Texas



Treatment or Trial



1995-1996



Birth

Cancer
Diagnosis



1995, age 5

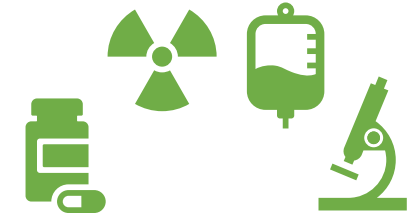


Louisiana

Biomarkers



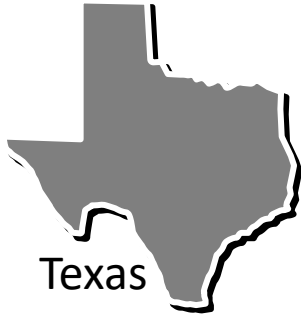
Outcome



Treatment or Trial

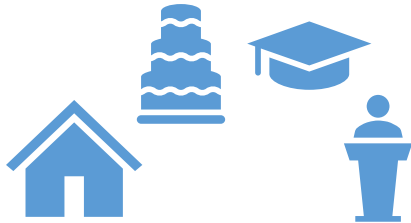


1995-1996



Texas

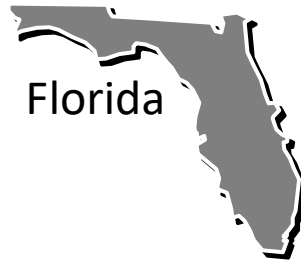
Healthcare
visit



Life events



2015, age 20



Florida





Birth

Cancer
Diagnosis

1995, age 5



Biomarkers



Outcome

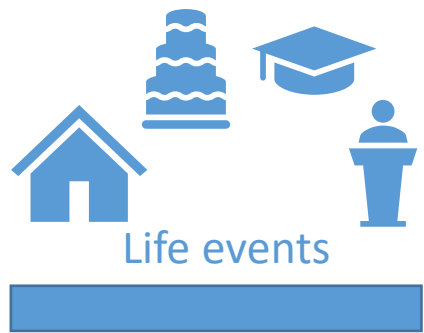
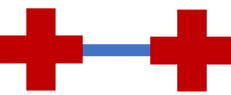


Treatment or Trial

1995-1996

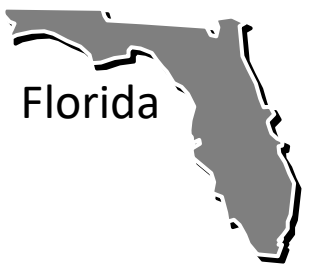


Healthcare
visit



Life events

2015, age 20

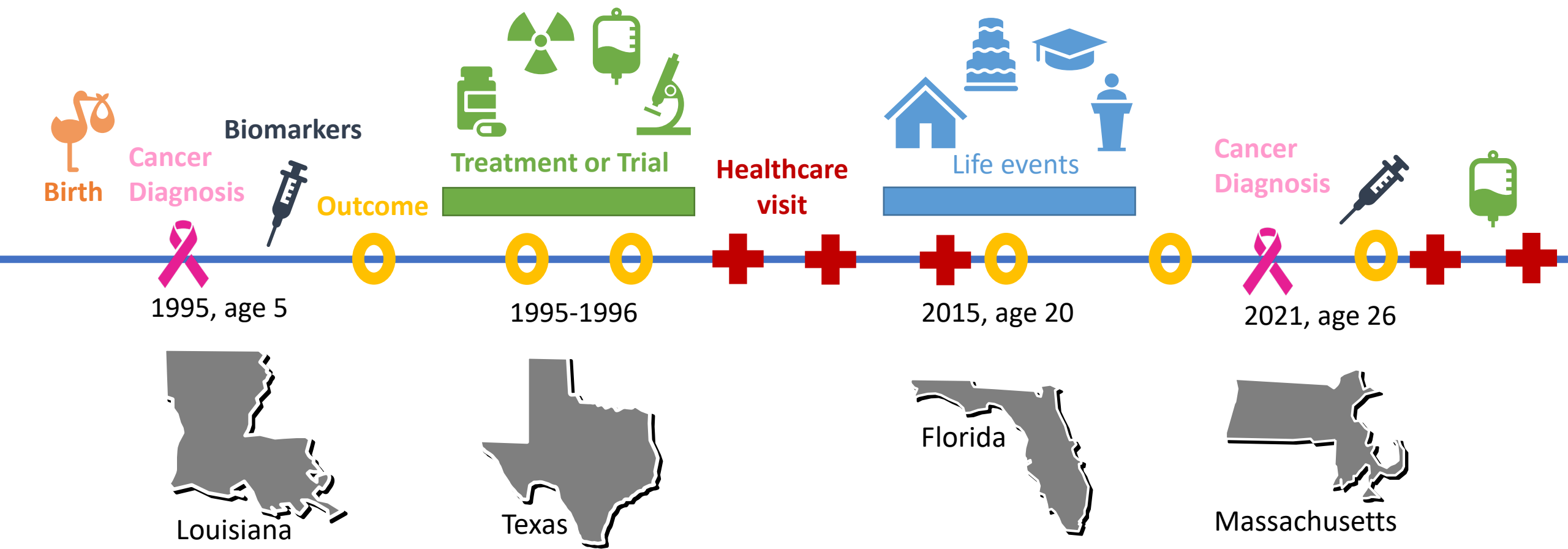


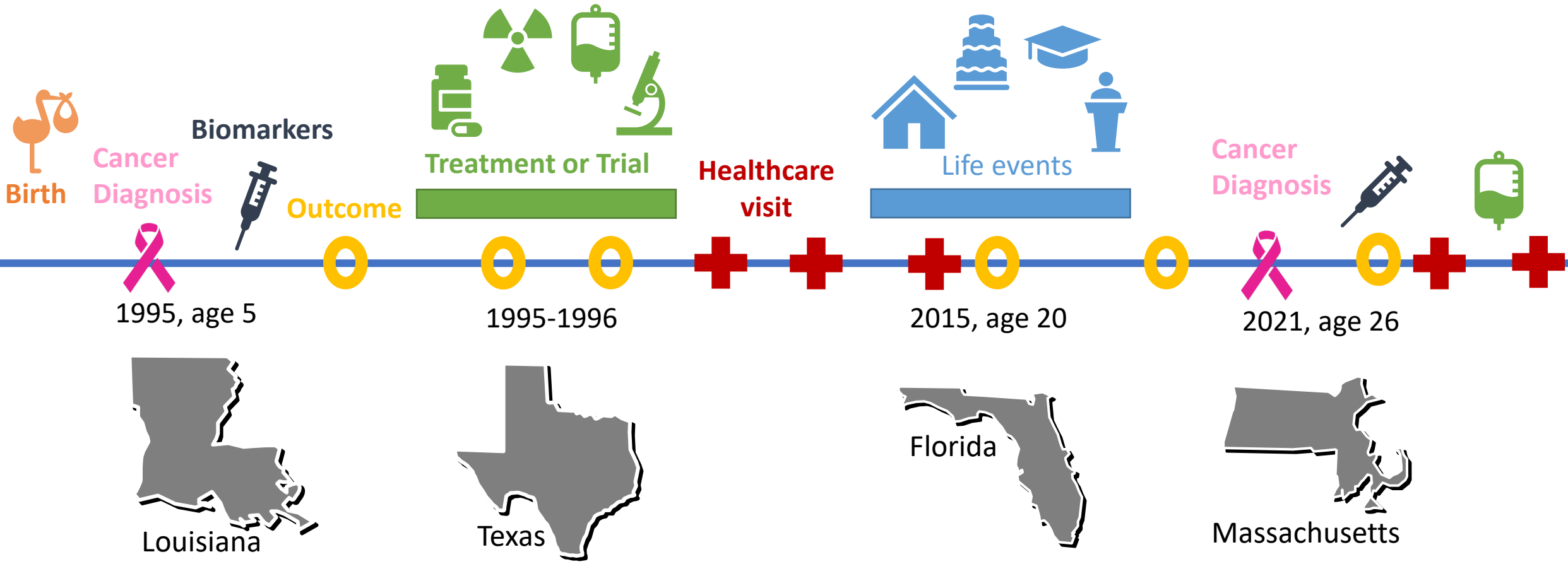
Cancer
Diagnosis

2021, age 26



Enrich with patient-level genomic, socio-demographic, and other clinical data





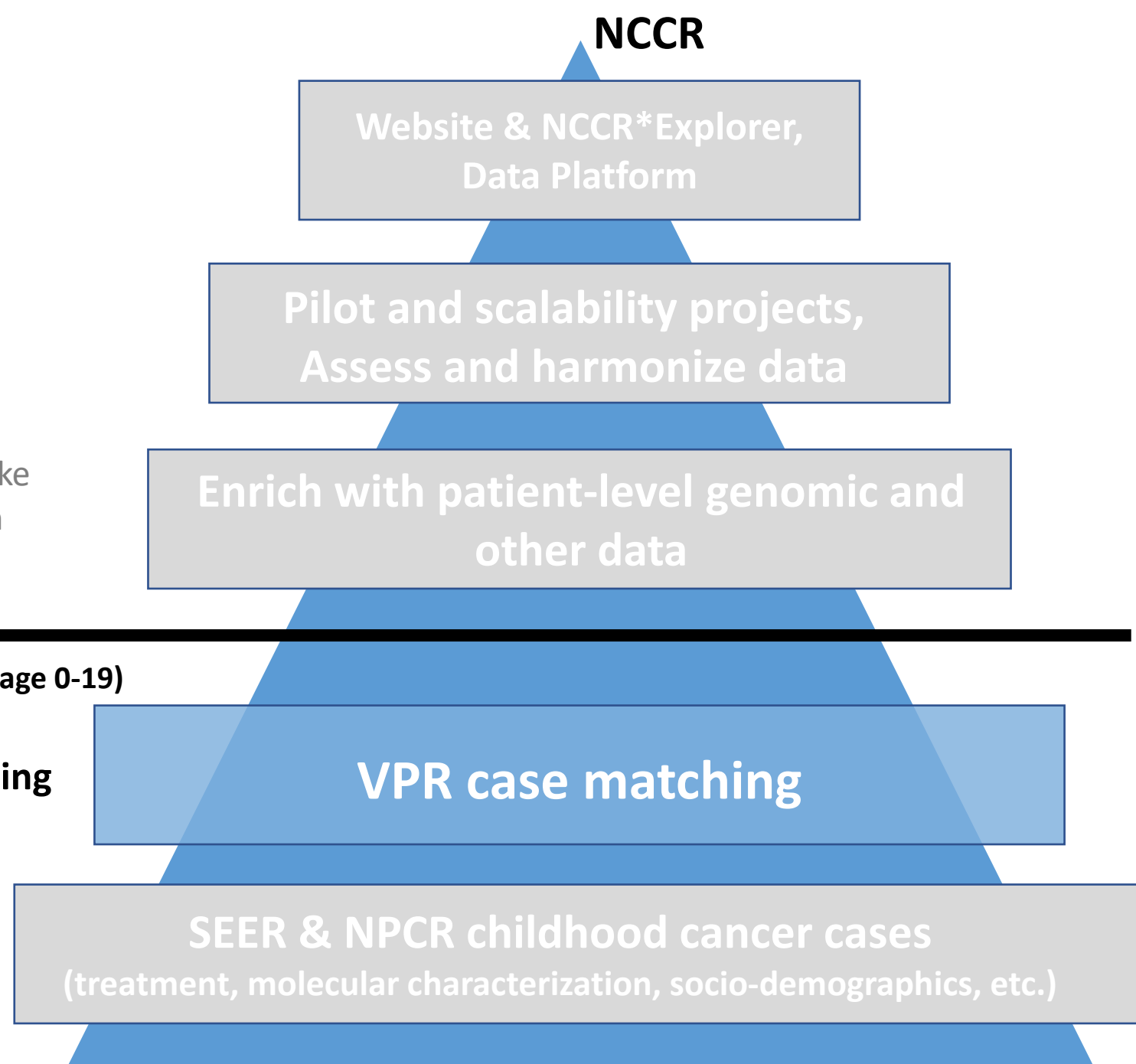
Infrastructure that allows us to accurately identify and match patients over time

CCDI > NCCR > NAACCR
Virtual Pooled Registry
(VPR)

- Communicate progress!
- Pilots like Birth Records, Whole Slide Imaging, Medicaid
- Other efforts to improve data quality and resources with CDC, HemOnc.org, DOE
- Linkages from detailed, non-registry sources like Cancer Centers, COG, Pediatric Proton/Photon Registry

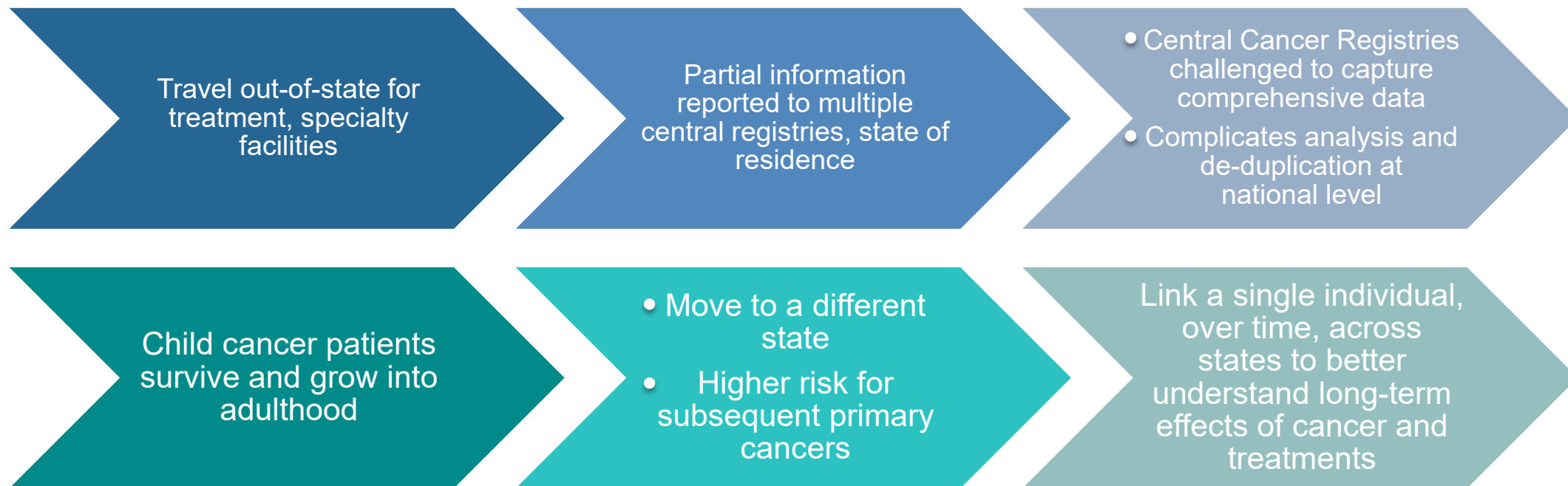
Census of all childhood cancer cases (age 0-19)

- **Virtual Pooled Registry NAACCR**
 - **De-duplication & longitudinal matching**
 - **9 states in 2022**
 - **Enable survivorship studies**
- High-quality PII/PHI-based matching of individuals across many data sources
- Rich data from SEER registry abstracts (since 1995; expanding to <40 year-olds)



NCCR & Virtual Pooled Registry



Why?



- VPR includes 43 central cancer registries who have agreed to perform linkages with clearly defined cohorts
 - Public health surveillance activity that enables identification, matching, and counting of primary and subsequent neoplasms among children and later in life
 - Obtain true incidence patterns
 - Measure the true risk of subsequent primaries and late effects of treatment



NCCR & VPR – Next Steps

- 
- Complete linkage between registries in NCCR and VPR
 - Enable better linkage of patients across registries and improve data quality by sharing case information
 - Quality control to improve identification of subsequent primaries
- 

Opportunities to use NCCR data under CCDI

Better understand disparities in care

Children with cancer have complicated patterns of care in the US:

- Children's Oncology Group (COG) runs the majority of clinical trials for pediatric cancer
- COG facilities provide state-of-the-art care, however:
 - 60% of patients age <29 enroll in trials
 - Prior studies report trial enrollment varies by age and cancer site
- **What patients are not seen at COG facilities?**

Solutions:

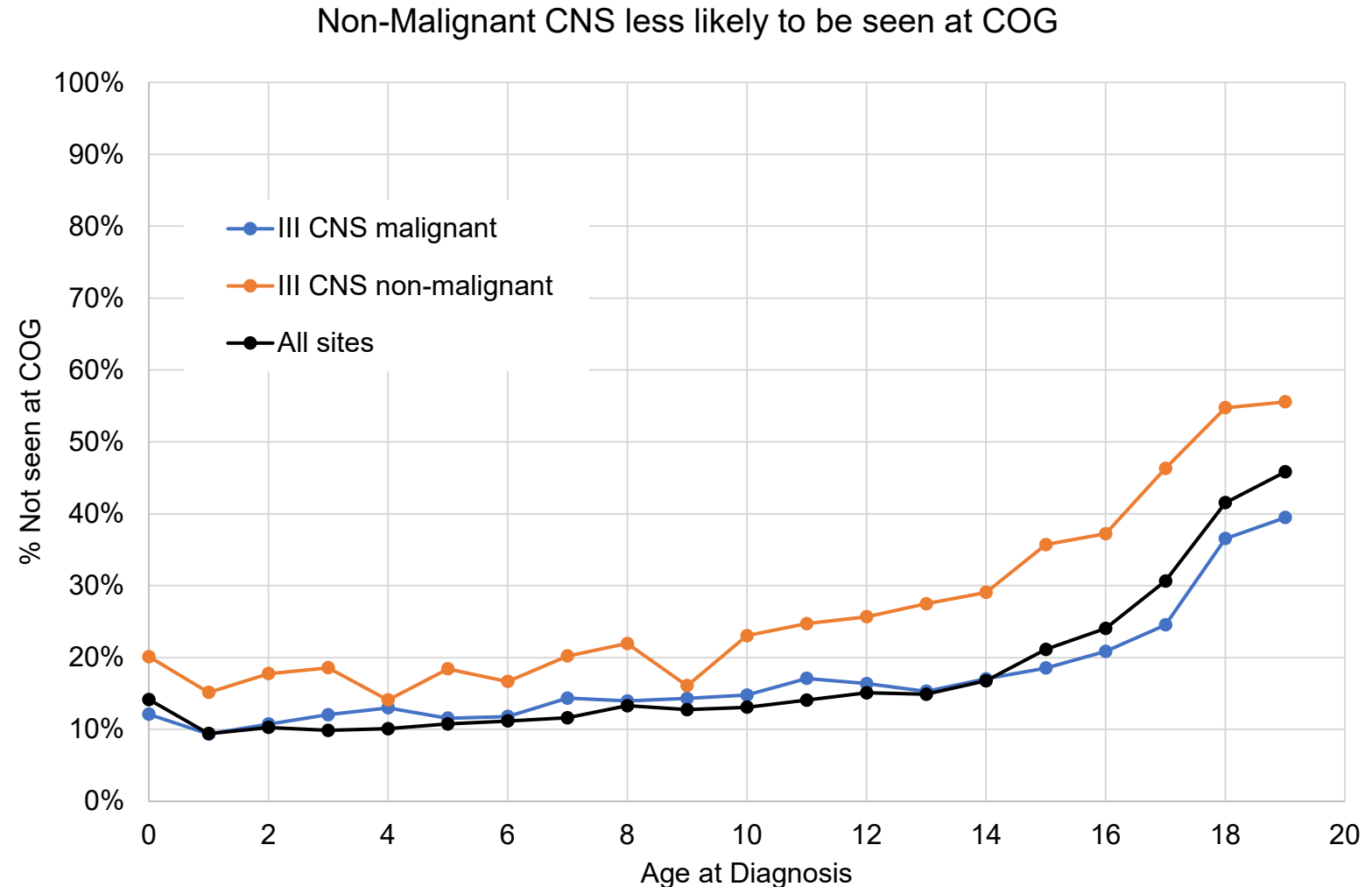
- Evaluate registry data for evidence of care received in COG facilities
- Link with COG data and understand disparities in access to care

Results from SEER evaluation on visiting COG facilities

Approximately 75-80% of 73,400 patients <20 years old had least 1 visit to a COG facility from 2000 to 2018 in 13 SEER registries.

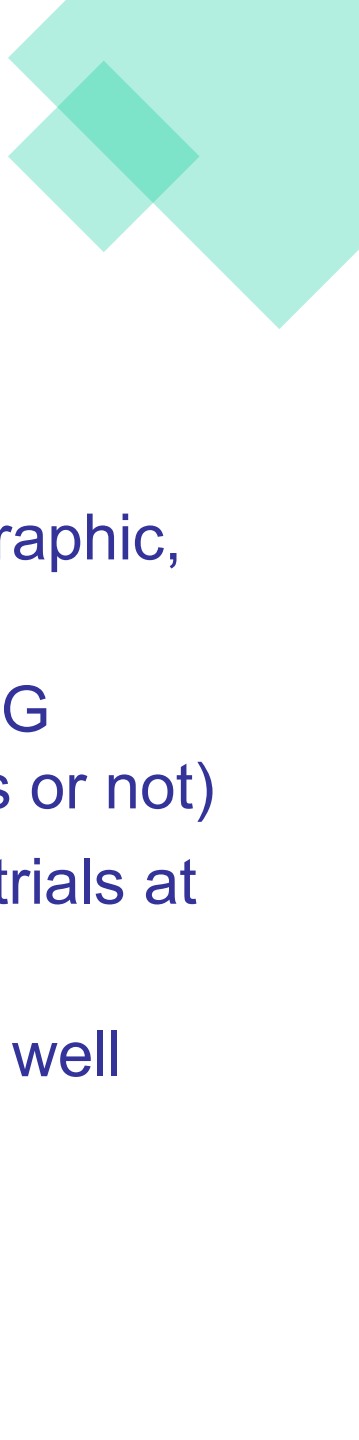
Patients not seen at COG facilities are:

- Older (aged 15-19)
- Female
- Black
- With certain cancer sites (CNS Non-Malignant) less likely to be treated at these state-of-the-art centers





COG Coverage – Next Steps

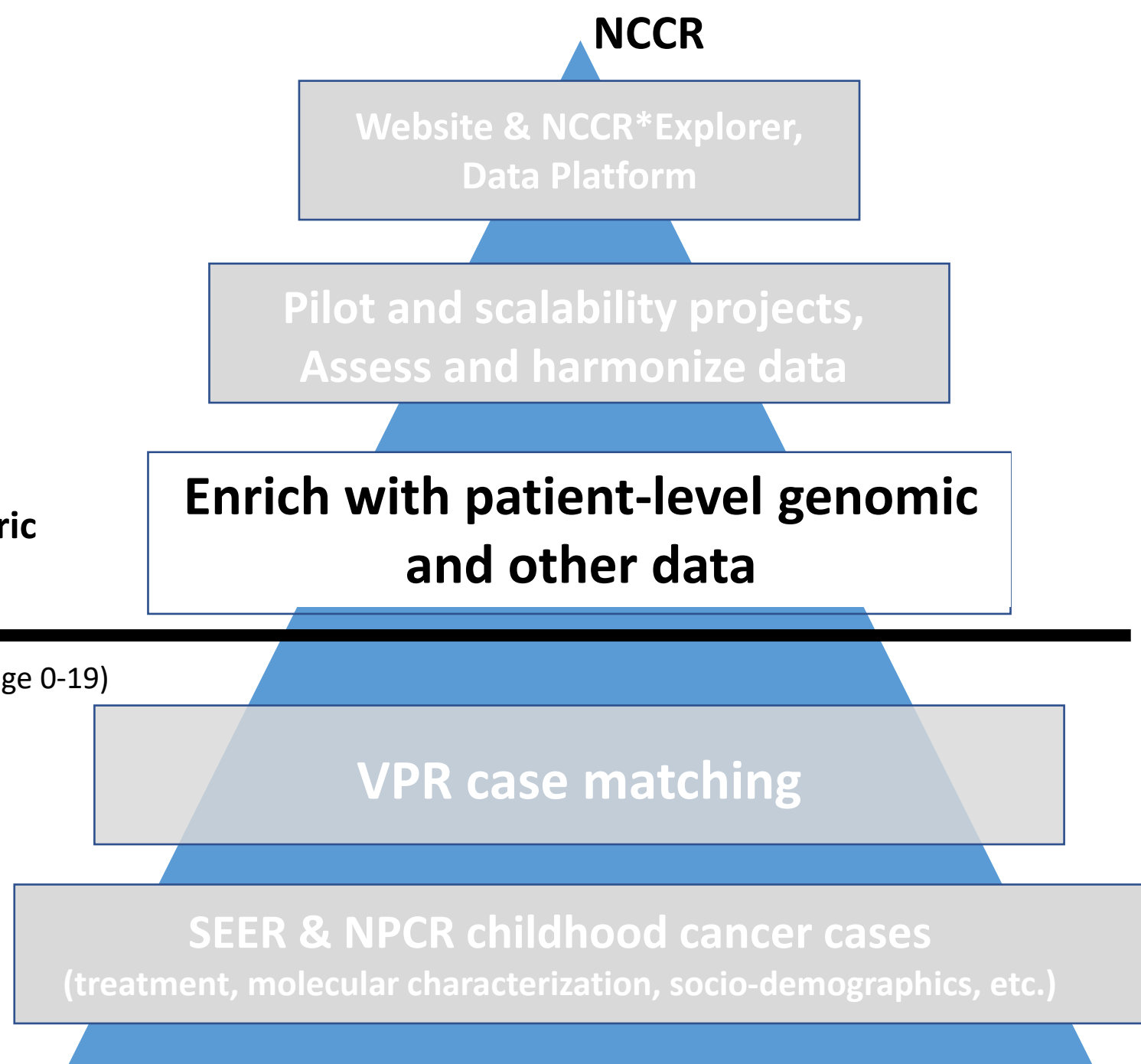
- Complete linkage with COG
 - Quality assurance assessment
 - Conduct analyses looking for demographic, geographic, and other disparities:
 - Proportion of patients seen at COG facilities (whether enrolled in trials or not)
 - Proportion of patients enrolled in trials at COG facilities
 - Identify population subgroups not well covered by COG
- 

CCDI > NCCR > Direct
Linkages to data providers

- Communicate progress!
- Pilots like Birth Records, Whole Slide Imaging, Medicaid
- Other efforts to improve data quality and resources with CDC, HemOnc.org, DOE
- **Linkages from detailed, non-registry sources like Cancer Centers, COG, Pediatric Proton/Photon Registry**

Census of all childhood cancer cases (age 0-19)

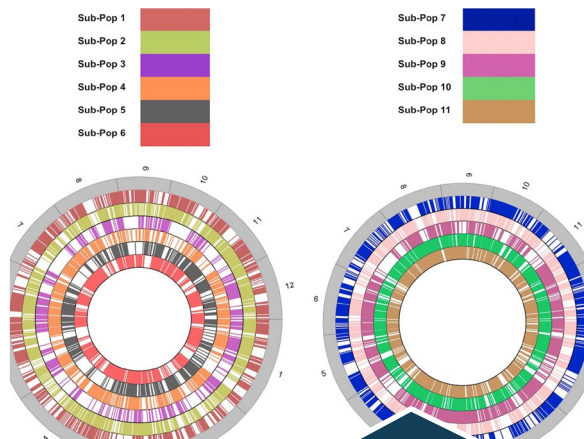
- Virtual Pooled Registry NAACCR
 - De-duplication & longitudinal matching
 - 9 states in 2022
 - Enable survivorship studies
- High-quality PII/PHI-based matching of individuals across many data sources
- Rich data from SEER registry abstracts (since 1995; expanding to <40 year-olds)



Important Categories of Data for CCDI from NCCR Cancer Centers



Clinical, treatment, and outcome data from clinical trials and the EHR



Molecular data including research sequencing and clinical molecular profiling



Availability and location of biospecimens, including germline and tumor DNA



Longitudinal population data from patients and survivors

NCCR Linkage Process

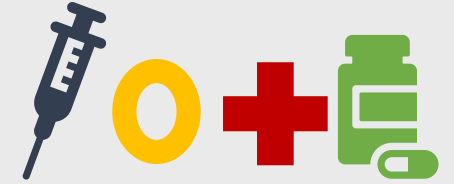
- Strategic assessment of potential data providers
- Develop a protocol
- Data providers approve protocol
- Participating registries approve protocol (ranging from 23-33 registries)
 - May require IRB modification
 - Review and approval for data release by registries
 - DUAs for each registry and each linkage
- Linkage
 - Depending on personally identifiable information, may require significant manual validation (e.g., COG)
 - Evaluate patient matching and data quality (completeness, accuracy etc.)
 - De-identified data submitted to NCCR Data Platform

CVS, Walgreens, RiteAid, Medicaid, Unlimited, United Healthcare

Linkages Complete, Data under Evaluation, Planning for updated data

Data Domain

- Medical and Pharmacy Claims



Importance

- Improve longitudinal matching
- Increase knowledge of comorbidities, treatment, recurrence

Data Details

- Date of prescription, medication information; Date of service, diagnosis codes, procedure codes, medication or treatment information

Data Domain

- Address History



Importance

- Improve accuracy of longitudinal matching for children who move or change names over their lifespan
- Link cases when patients move

Data Details

- Address history since 1995 matched to address at diagnosis
- SEER saw success in adults and increased match rates
- Identify adults with the same address as child's at diagnosis

Enhanced data from Cancer Centers and Hospitals

Some Linkages Complete, Others In Process

Data Domain

- Real-world clinical data



Importance

- Increase knowledge of comorbidities, treatment, recurrence, biomarkers, radiology and pathology reports, outcomes, comorbidities

Data Details

- Date of service, diagnosis codes, procedure codes, medication or treatment information (Chemotherapy, dose, dates; Radiation site, dose, fractions)
- Gene, variant, structural rearrangements
- Site, histology, grade, stage
- Survivorship, family studies information

Children's Oncology Group clinical trials database (2007-2017; 2015-current)

Linkage in process
now

Data Domain

- Clinical Trial Enrollment
- Address History
- Pathology Report



Importance

- Improve longitudinal matching
- Clinical trial participation and coordination with COG
- Detailed pathology, patient demographics, diagnosis

Data Details

- Patient and parent address and patient demographics
- ICD-O histology, behavior, topology; Stage; Diagnosis date
- Trial enrollment
- Consent for recontact studies

State Health Department

Birth Records

Summer 2022

Data Domain

- Parental Address History
- Potential risks to develop cancer from around the time of birth related to geography or other factors



Importance

- Improve accuracy of matching prior to child's cancer diagnosis and capture parent names
- Well-established gestational and perinatal risk factors for childhood cancer
- Less-established risk factors in need of further study

Data Details

- Parent names, subsequently linked to parent's LexisNexis address history
- Birth weight, parental age, mode of birth, parental smoking, maternal obesity

Pediatric Proton and Photon Consortium Registry (PPCR)

Fall 2022

Data Domain

- Clinical research
- Detailed treatment
- Outcomes

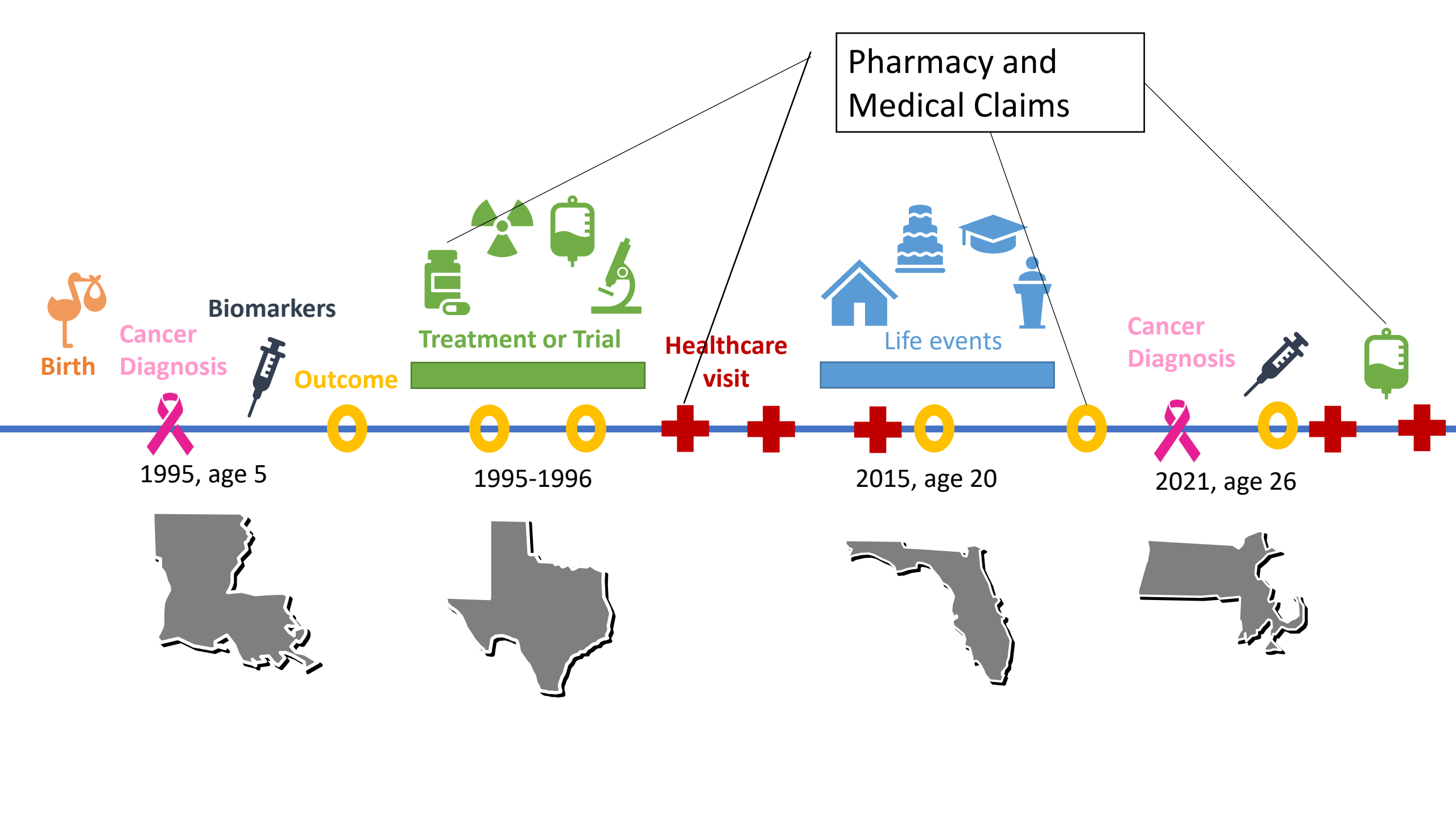


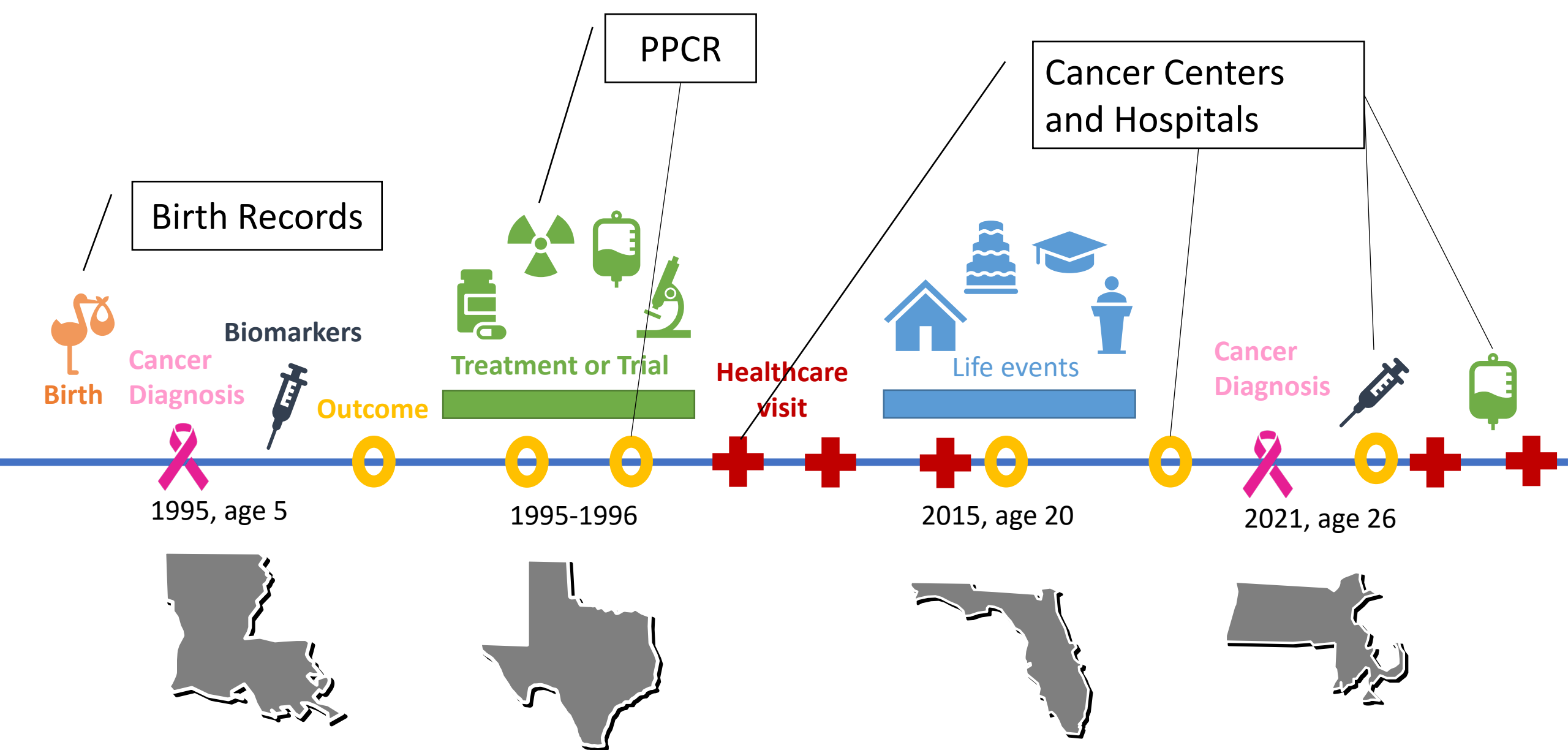
Importance

- Increase knowledge of treatment
- Improve capture and standardization of radiotherapy
- Reduce manual abstraction
- Improve knowledge of adverse outcomes like secondary malignancies and late effects

Data Details

- Comprehensive data on disease, treatment, and clinical outcomes of pediatric cancer patients receiving any radiation modality





Birth Records

PPCR

Cancer Centers and Hospitals



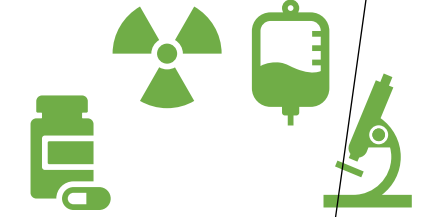
Birth

Cancer Diagnosis

Biomarkers



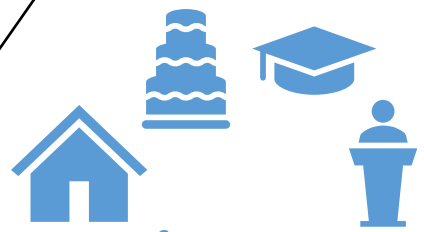
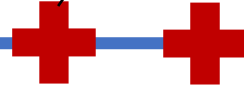
Outcome



Treatment or Trial



Healthcare visit



Life events



Cancer Diagnosis



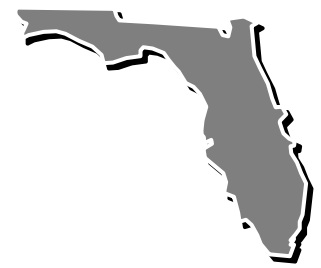
1995, age 5



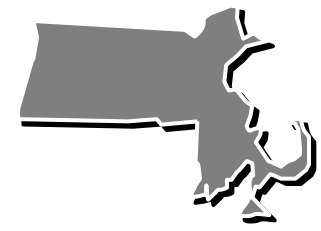
1995-1996

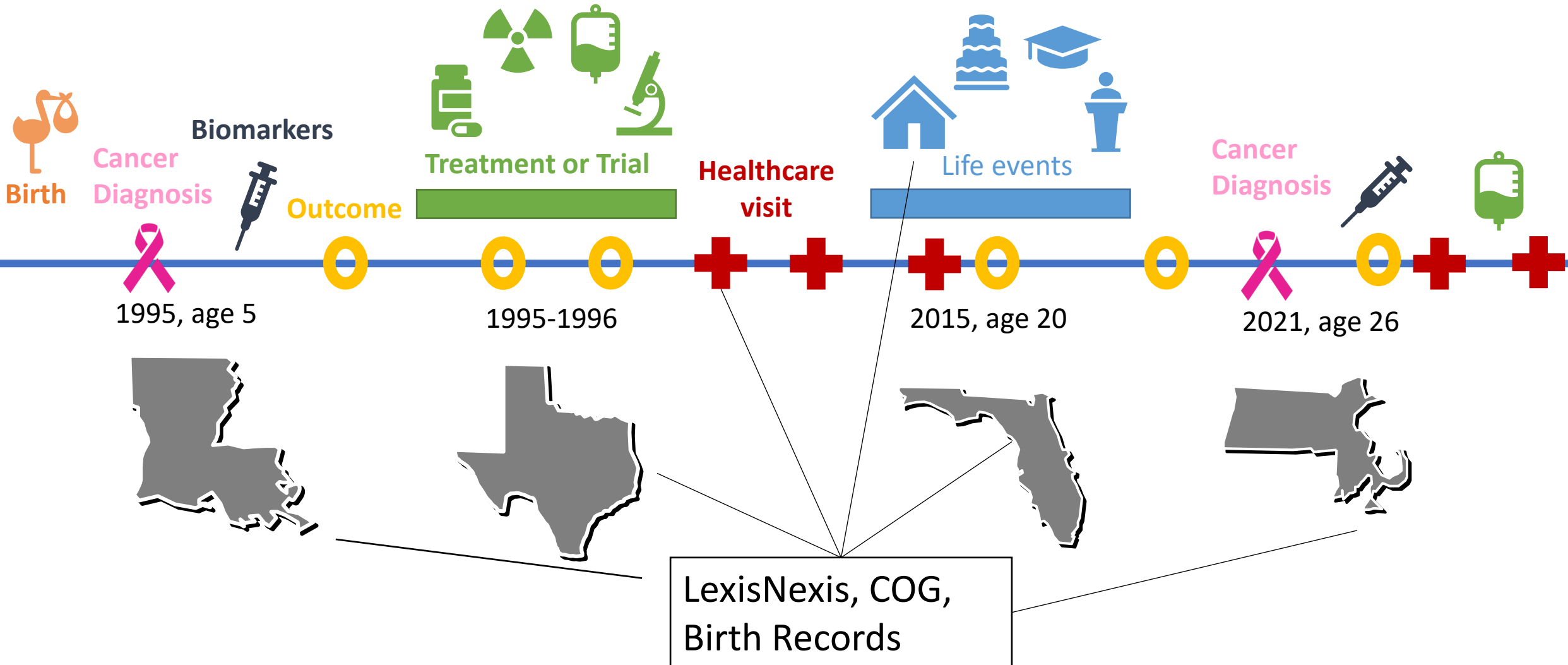


2015, age 20



2021, age 26





Birth

Cancer Diagnosis

Biomarkers

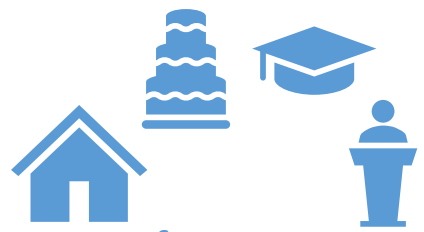
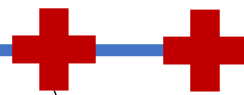


Outcome



Treatment or Trial

Healthcare visit



Life events



Cancer Diagnosis

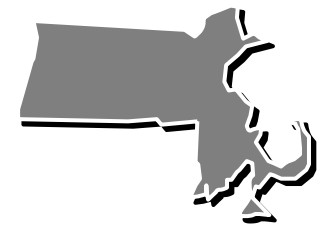
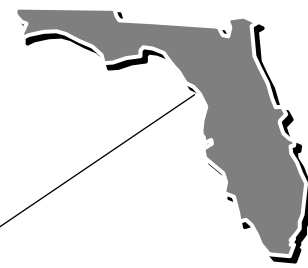
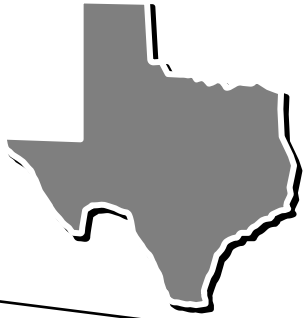


1995, age 5

1995-1996

2015, age 20

2021, age 26



LexisNexis, COG,
Birth Records



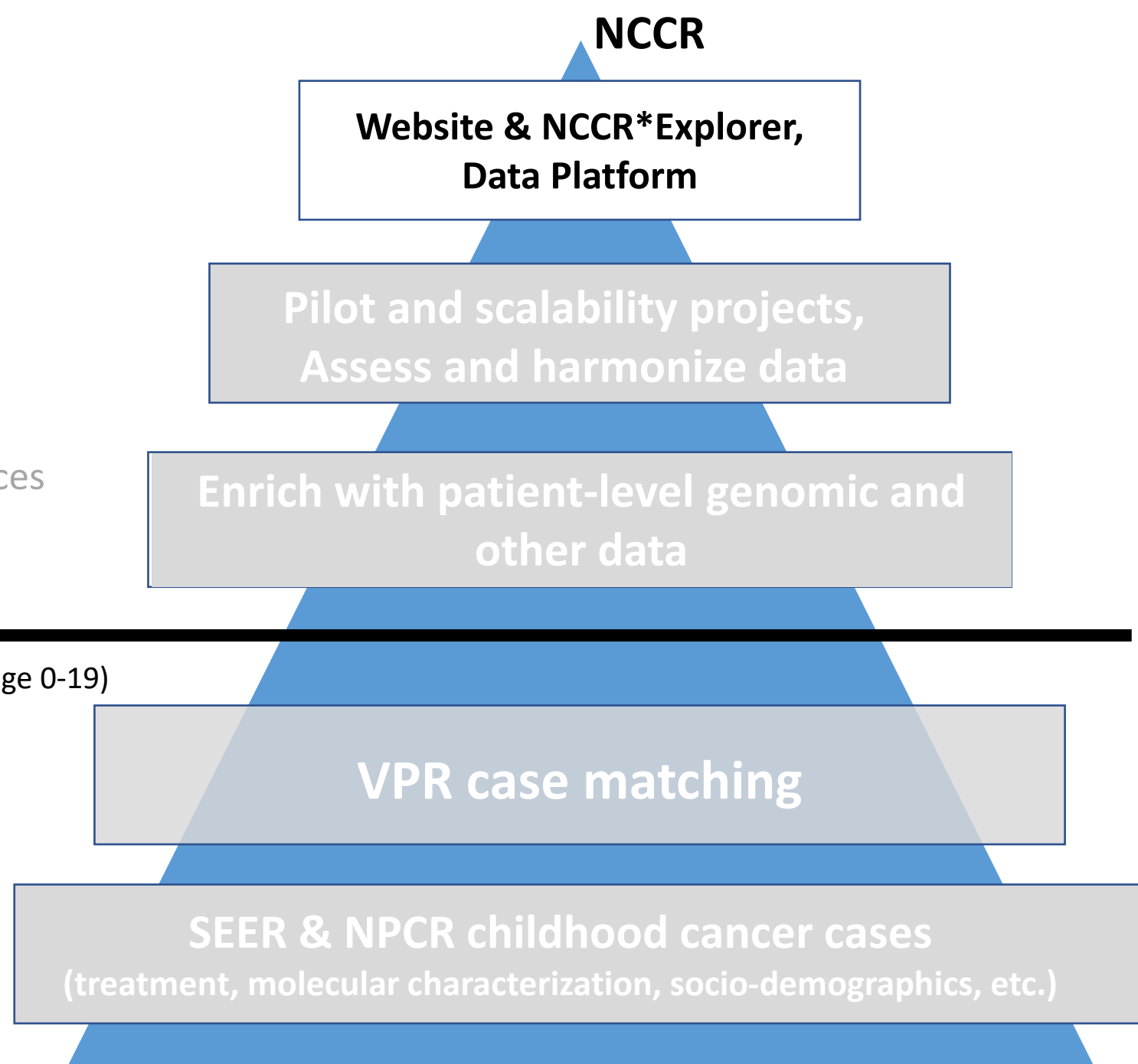
How do we share data?

- **Communicate progress!**

- Pilots like Birth Records, Whole Slide Imaging, Medicaid
- Other efforts to improve data quality and resources with CDC, HemOnc.org, DOE
- Linkages from detailed, non-registry sources like Cancer Centers, COG, Pediatric Proton/Photon Registry

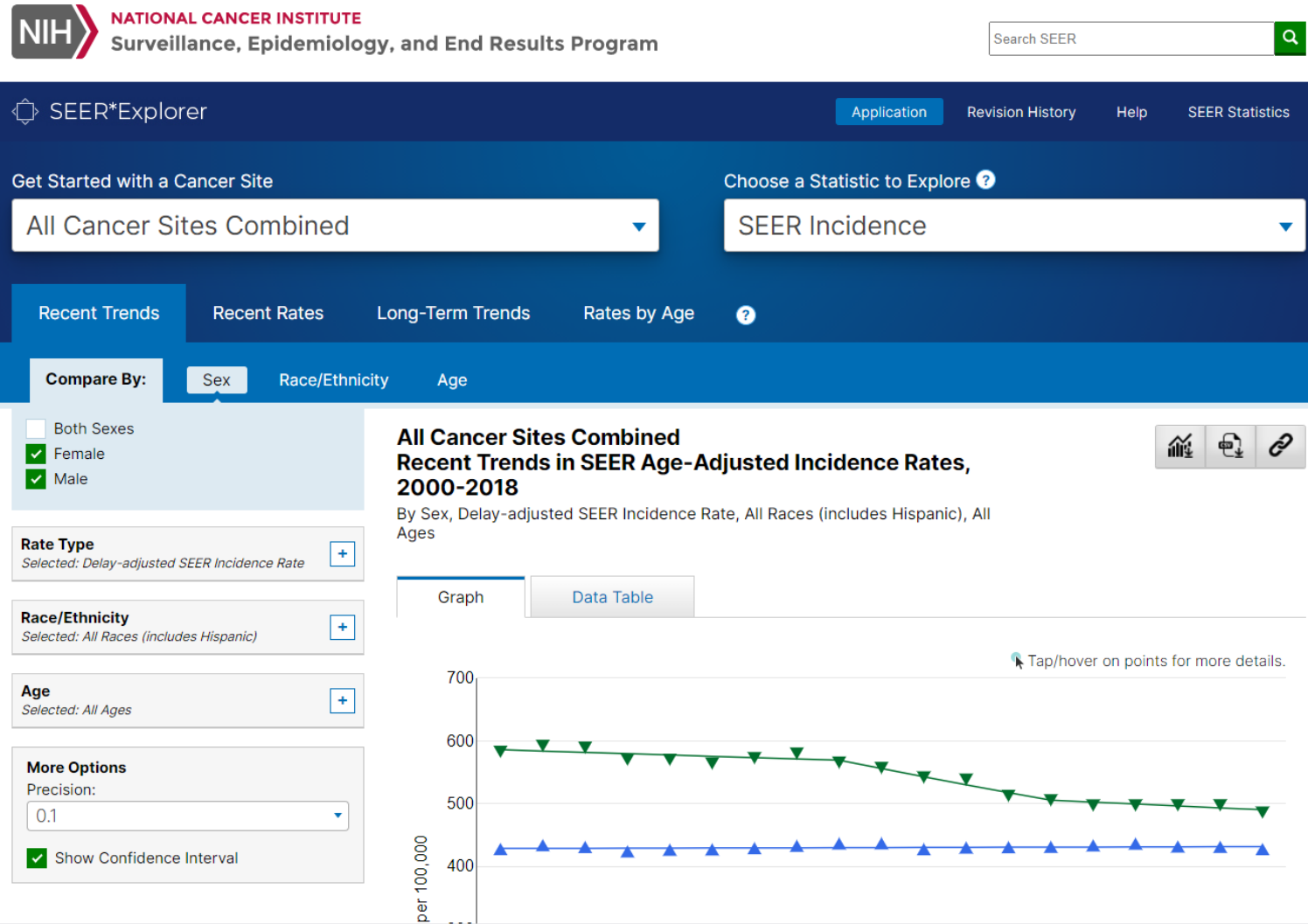
Census of all childhood cancer cases (age 0-19)

- Virtual Pooled Registry NAACCR
 - De-duplication & longitudinal matching
 - 9 states in 2022
 - Enable survivorship studies
- High-quality PII/PHI-based matching of individuals across many data sources
- Rich data from SEER registry abstracts (since 1995; expanding to <40 year-olds)



NCCR* Explorer

- Pre-calculated statistics in dynamic tables and plots based on user criteria
- Site-specific age groups based on clinical significance
- Histology-based groupings
- No geographic identifiers to minimize risk of reidentification of small numbers
- Over time will add new variables not collected by registries, e.g., Cancer Center Supplement projects



How do we share data from linkages back to registries?

- NCCR-participating registries review and approve linkage protocols
 - Data providers and registries negotiate what data can be shared directly with central cancer registries
- Registries can submit requests to use the controlled access NCCR Data Platform (de-identified)
- Public, aggregate statistics through NCCR*Explorer



Metadata



Chairs:

- Sumit Gupta, MD, PhD, FRCP (University of Toronto)
- Todd Gibson, PhD (NCI)

Members: Oncologists, pathologists, cancer registrars, researchers, epidemiologists

Data Quality



Chairs:

- Fernanda Silva-Michels, MSc, PhD, CTR (NAACCR)
- Gonçalo Forjaz, DVM, MSc, CTR (NCI)

Members: Cancer registrars, informaticists, epidemiologists, researchers

Data Products



Chairs:

- Dennis Deapen, DrPH (USC)
- Amie Hwang, MPH, PhD (USC)

Members: Central cancer registries, researchers, epidemiologists, informaticists

Data Access & Release



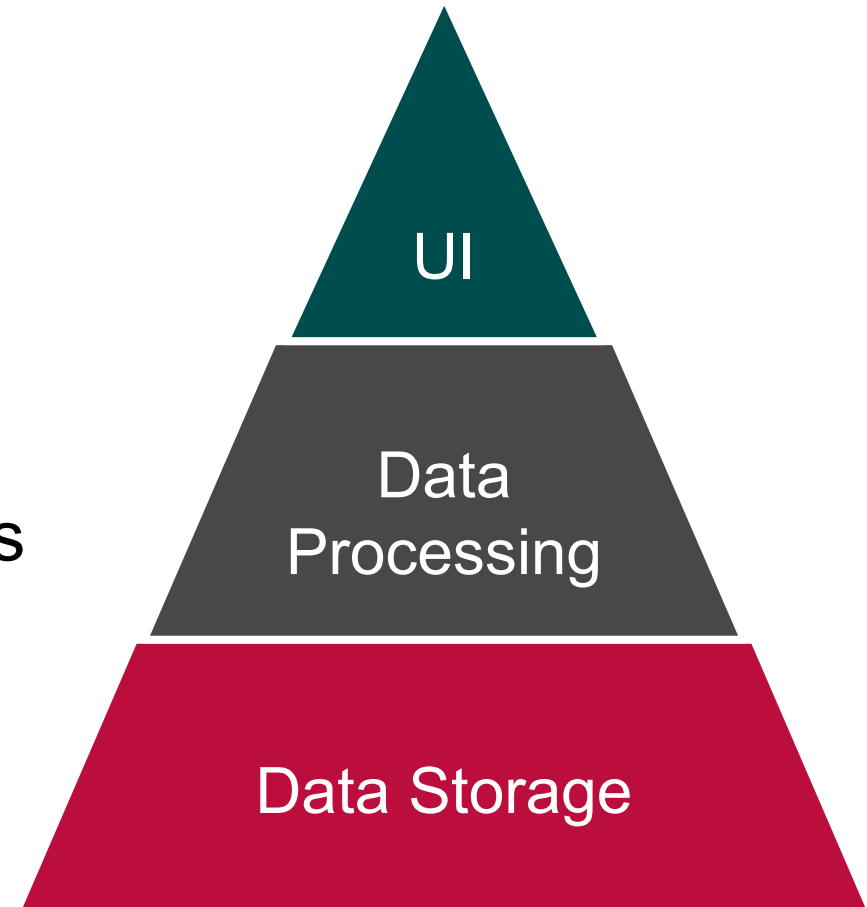
Chairs:

- Stephanie Hill, MPH, CTR (NAACCR)
- Karen L. Knight, MS, (NAACCR)

Members: Central cancer registries, researchers, epidemiologists, informaticists, IRB specialists

NCCR Data Platform goal: Enable controlled access to data

- Secure, authorized data sharing
- Integrate with CCDI federated system
- Support searching data using complex queries and building cohorts that meet researcher's criteria
- Built-in governance to request data and cohorts from multiple data providers
- Link data from multiple sources using PII & privacy-preserving record linkages
- Enhance registry data with linked data





Pediatric Cancer Stage based on the Toronto Consensus of 2014

Paediatric cancer stage in population-based cancer registries: the Toronto consensus principles and guidelines



Sumit Gupta, Joanne F Aitken, Ute Bartels, James Brierley, Mae Dolendo, Paola Friedrich, Soad Fuentes-Alabi, Claudia P Garrido, Gemma Gatta, Mary Gospodarowicz, Thomas Gross, Scott C Howard, Elizabeth Molyneux, Florencia Moreno, Jason D Pole, Kathy Pritchard-Jones, Oscar Ramirez, Lynn A G Ries, Carlos Rodriguez-Galindo, Hee Young Shin, Eva Steliarova-Foucher, Lillian Sung, Eddy Supriyadi, Rajaraman Swaminathan, Julie Torode, Tushar Vora, Tezer Kutluk, A Lindsay Frazier

Population-based cancer registries generate estimates of incidence and survival that are essential for cancer surveillance, research, and control strategies. Although data on cancer stage allow meaningful assessments of changes in cancer incidence and outcomes, stage is not recorded by most population-based cancer registries. The main method of staging adult cancers is the TNM classification. The criteria for staging paediatric cancers, however, vary by diagnosis, have evolved over time, and sometimes vary by cooperative trial group. Consistency in the collection of staging data has therefore been challenging for population-based cancer registries. We assembled key experts and stakeholders (oncologists, cancer registrars, epidemiologists) and used a modified Delphi approach to establish principles for paediatric cancer stage collection. In this Review, we make recommendations on which staging systems should be adopted by population-based cancer registries for the major childhood cancers, including adaptations for low-income countries. Wide adoption of these guidelines in registries will ease international comparative incidence and outcome studies.

Introduction

cancer stage by population-based cancer registries, and

Lancet Oncol 2016; 17: e163-72


Division of Haematology/
Oncology, Hospital for Sick
Children, Toronto, ON, Canada
(S Gupta PhD, U Bartels MD,
L Sung PhD); Department of
Paediatrics, Faculty of
Medicine, University of
Toronto, Toronto, ON, Canada
(S Gupta, U Bartels, L Sung);
Cancer Council Queensland,
Fortitude Valley, Brisbane,
QLD, Australia (J F Aitken PhD);
Department of Radiation
Oncology, Princess Margaret
Hospital, Toronto, ON, Canada

PMID: 27300676

DOI: [10.1016/S1470-2045\(15\)00539-2](https://doi.org/10.1016/S1470-2045(15)00539-2)

COMMENT | VOLUME 2, ISSUE 3, P158-159, MARCH 01, 2018

The Toronto Guidelines: a practical means for childhood cancer staging

Nickhill Bhakta  • Carlos Rodriguez-Galindo

Published: January 23, 2018 • DOI: [https://doi.org/10.1016/S2352-4642\(18\)30024-5](https://doi.org/10.1016/S2352-4642(18)30024-5) •



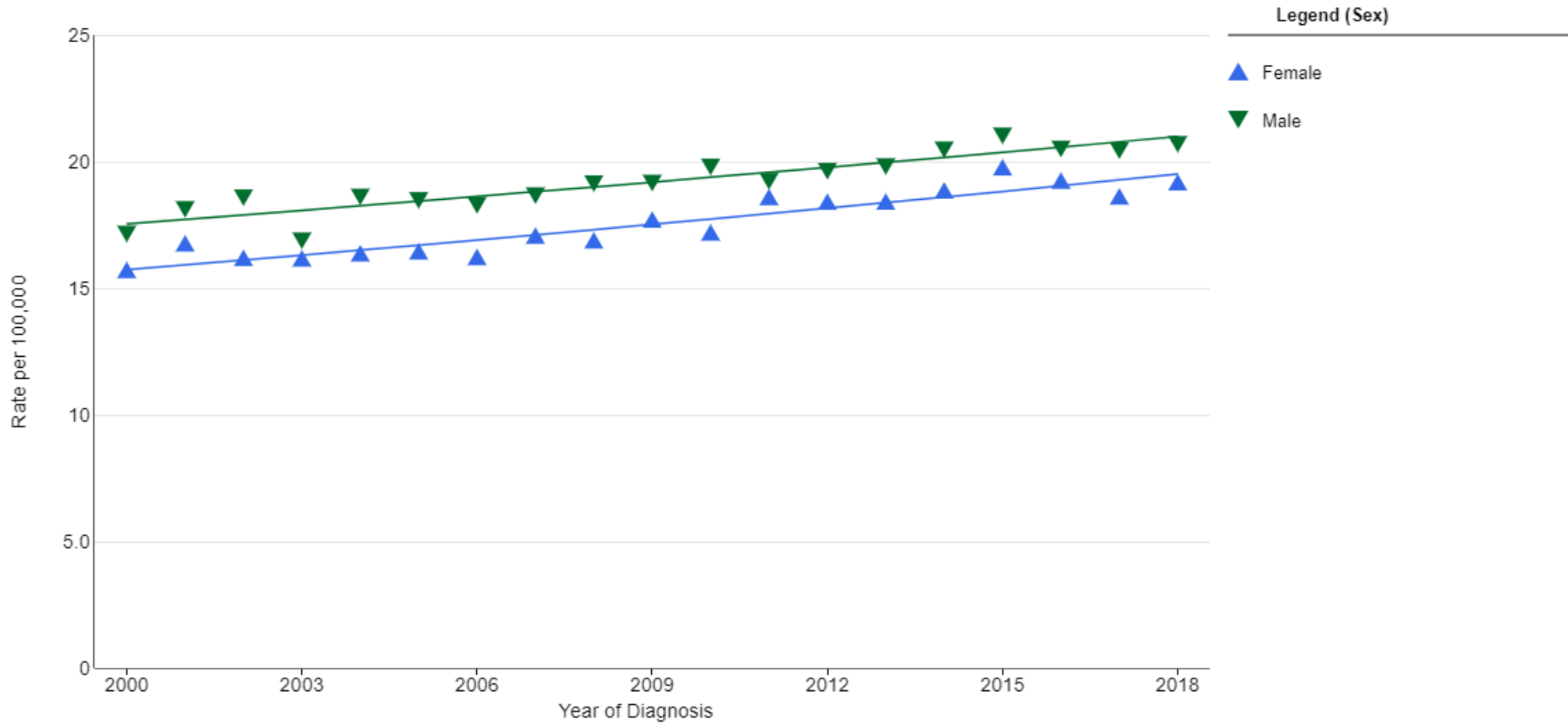
A meaningful comparison of paediatric cancer outcomes over time or by geographical location requires a standardised and systematic collection of data on incident cases, survival

PMID: 30169247

DOI: [10.1016/S2352-4642\(18\)30024-5](https://doi.org/10.1016/S2352-4642(18)30024-5)

Looking ahead

All Cancer Sites Combined
Recent Trends in SEER Age-Adjusted Incidence Rates, 2000-2018
By Sex, Delay-adjusted SEER Incidence Rate, All Races (includes Hispanic), Ages < 20



Created by <https://seer.cancer.gov/explorer> on Fri May 21 2021.
 SEER 21 areas [<http://seer.cancer.gov/registries/terms.html>] (San Francisco, Connecticut, Detroit, Hawaii, Iowa, New Mexico, Seattle, Utah, Atlanta, San Jose-Monterey, Los Angeles, Alaska Native Registry, Rural Georgia, California excluding SF/SJM/LA, Kentucky, Louisiana, New Jersey, Georgia excluding ATL/RG, Idaho, New York and Massachusetts).
 Rates are per 100,000 and are age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1130).
 The Annual Percent Change (APC) and Average Annual Percent Change (AAPC) estimates were calculated from the underlying rates using the Joinpoint Trend Analysis Software [<http://surveillance.cancer.gov/joinpoint>], Version 4.9, March 2021, National Cancer Institute.
 The APC's/AAPC's direction is "rising" when the entire 95% confidence interval (C.I.) is above 0, "falling" when the entire 95% C.I. is lower than 0, otherwise, the trend is considered stable.
 Rates for American Indians/Alaska Natives only include cases that are in a Purchased/Referred Care Delivery Area (PRCDA). See SEER Race Recode Documentation for American Indian/Alaskan Native Statistics [http://seer.cancer.gov/seerstat/variables/seer/race_ethnicity/#ai-an].
 Hispanics and Non-Hispanics are not mutually exclusive from whites, blacks, Asian/Pacific Islanders, and American Indians/Alaska Natives. Incidence data for Hispanics and Non-Hispanics are based on the NAACCR Hispanic Latino Identification Algorithm (NHIA) and exclude cases from the Alaska Native Registry. See SEER Race Recode Documentation for Spanish-Hispanic-Latino Ethnicity [http://seer.cancer.gov/seerstat/variables/seer/race_ethnicity/#hispanic].
 See SEER*Explorer Cancer Site Definitions [<https://seer.cancer.gov/explorer/cancer-sites.html>] for details about the coding used for SEER Incidence data.

What is the outlook for children and adolescents with cancer?

The overall outlook for children and adolescents with cancer has improved greatly over the last half-century. In the mid-1970s, 58% of children (ages 0 to 14 years) and 68% of adolescents (ages 15 to 19 years) diagnosed with cancer survived at least 5 years (1). In 2010–2016, 84.1% of children and 85.3% of adolescents diagnosed with cancer survived at least 5 years (3).

Although survival rates for most childhood cancers have improved in recent decades, the improvement has been especially dramatic for a few cancers, particularly acute lymphoblastic leukemia, which is the most common childhood cancer. Improved treatments introduced beginning in the 1960s and 1970s raised the 5-year survival rate for children diagnosed with acute lymphoblastic leukemia at ages 0 to 14 years from 57% in 1975 to 92% in 2012 (4). The 5-year survival rate for children diagnosed with non-Hodgkin lymphoma at ages 0 to 14 years has also increased dramatically, from 43% in 1975 to 91% in 2012 (4).

Because of these survival improvements, in more recent years brain cancer has replaced leukemia as the leading cause of cancer death among children (5).

By contrast, survival rates remain very low for some cancer types, for some age groups, and for some cancers within a site. For example, half of children with diffuse intrinsic pontine glioma (a type of brain tumor) survive less than 1 year from diagnosis (6). Among children with Wilms tumor (a type of kidney cancer), older children (those diagnosed between ages 10 and 16 years) have lower 5-year survival rates than younger children (7). For soft tissue sarcomas, 5-year survival rates in 2008–2014 among children and adolescents ages 0 to 19 years ranged from 65% (rhabdomyosarcoma) to 95% (chondrosarcoma) (8), but children with sarcomas who present with metastatic disease have much lower 5-year survival rates. And the 5-year survival rate for acute lymphoblastic leukemia in 2008–2014 was 91% for children younger than 15 years, compared with 74% for adolescents ages 15 to 19 years (8).

Some evidence suggests that adolescents and young adults with acute lymphoblastic leukemia may have better outcomes if they are treated with pediatric treatment regimens than if they receive adult treatment regimens (9). The improvement in 5-year survival rates for 15- to 19-year-olds with acute lymphoblastic leukemia may reflect greater use of these pediatric treatment regimens.

[https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet#:~:text=In%20the%20mid%2D1970s%2C%2058,least%205%20years%20\(3\)](https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet#:~:text=In%20the%20mid%2D1970s%2C%2058,least%205%20years%20(3))



What does the NCCR mean for FCDS?



NCI and researchers use your work to evaluate treatment, outcomes, and long-term effects of childhood cancer



Linkages are available to Florida



What you have done since 1995 is contributing today and in the future



Florida is helping to grow rich data resources for rare cancers



**NATIONAL
CANCER
INSTITUTE**

www.cancer.gov

www.cancer.gov/espanol