

Childhood Cancer Data Initiative (CCDI): Overview, Progress, and Future

2022 CAC2 Annual Summit

Introductions

- Pediatric oncologist
- Clinical researcher
- Chief of NCI's Pediatric Oncology Branch
- Special Advisor to the NCI Director for Childhood Cancer
- Co-Chair of CCDI's Engagement Committee



Inaugural Chordoma Clinic, 2019

Special Advisor to the Director for Childhood Cancer

- Provides guidance to the NCI Director that highlights opportunities in childhood cancer research and gaps in treatment
- Assumes leadership role within CCDI to help coordinate activities, leverage opportunities, and advance progress
- Advises across NCI to identify opportunities to make advances for children and AYAs



YouTube Video with Drs. Sharpless and Widemann

Welcome Dr. Gregory Reaman



Joining NCI as CCDI Scientific Director

Official start at end of September

About CCDI

CCDI

BUILDING A
COMMUNITY CENTERED
AROUND CHILDHOOD
CANCER CARE AND
RESEARCH DATA



LEARN FROM
EVERY CHILD

DATA TYPES:

CLINICAL

TREATMENT

OUTCOME

MOLECULAR

BIOSPECIMEN

LONGITUDINAL

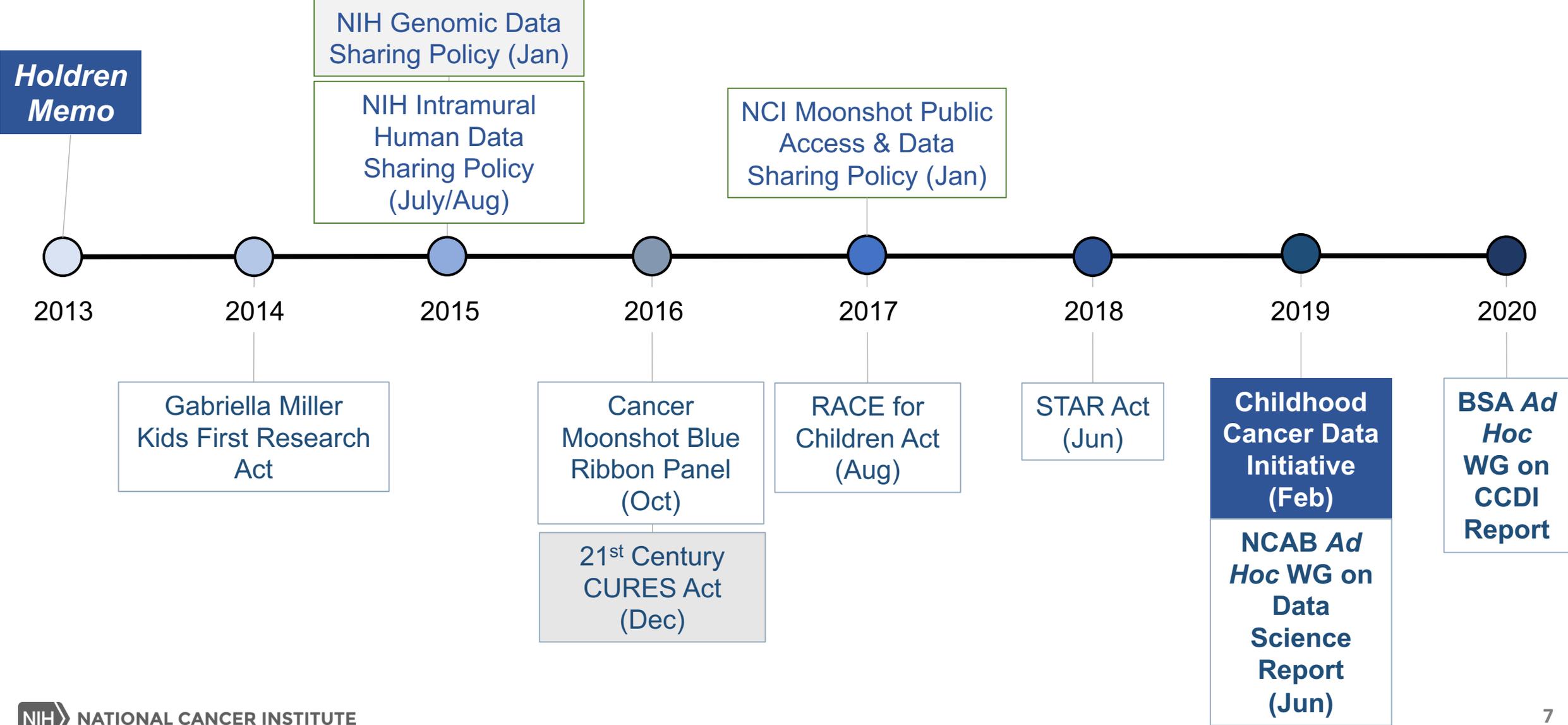
POPULATION

PROGRAM GOALS:

- DEVELOP NEW TREATMENTS
- IMPROVE EXISTING TREATMENTS
- IMPROVE OUTCOMES, QUALITY OF LIFE, AND SURVIVORSHIP

IMPROVING THE QUALITY, CONSISTENCY, ACCESS, AND
ACCESSIBILITY OF DATA FROM EVERY CHILD WILL
ALLOW US TO ACHIEVE OUR GOALS.

CCDI Builds on Momentum of Prior Research and Data Sharing Policy



Childhood Cancer Data Initiative

STAR Act Research Efforts



STAR Act biobanking efforts include the *COG Rare Tumor Populations Biobanking Project* – working in partnership with the Molecular Characterization Initiative to support specimen collection

CCDI 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



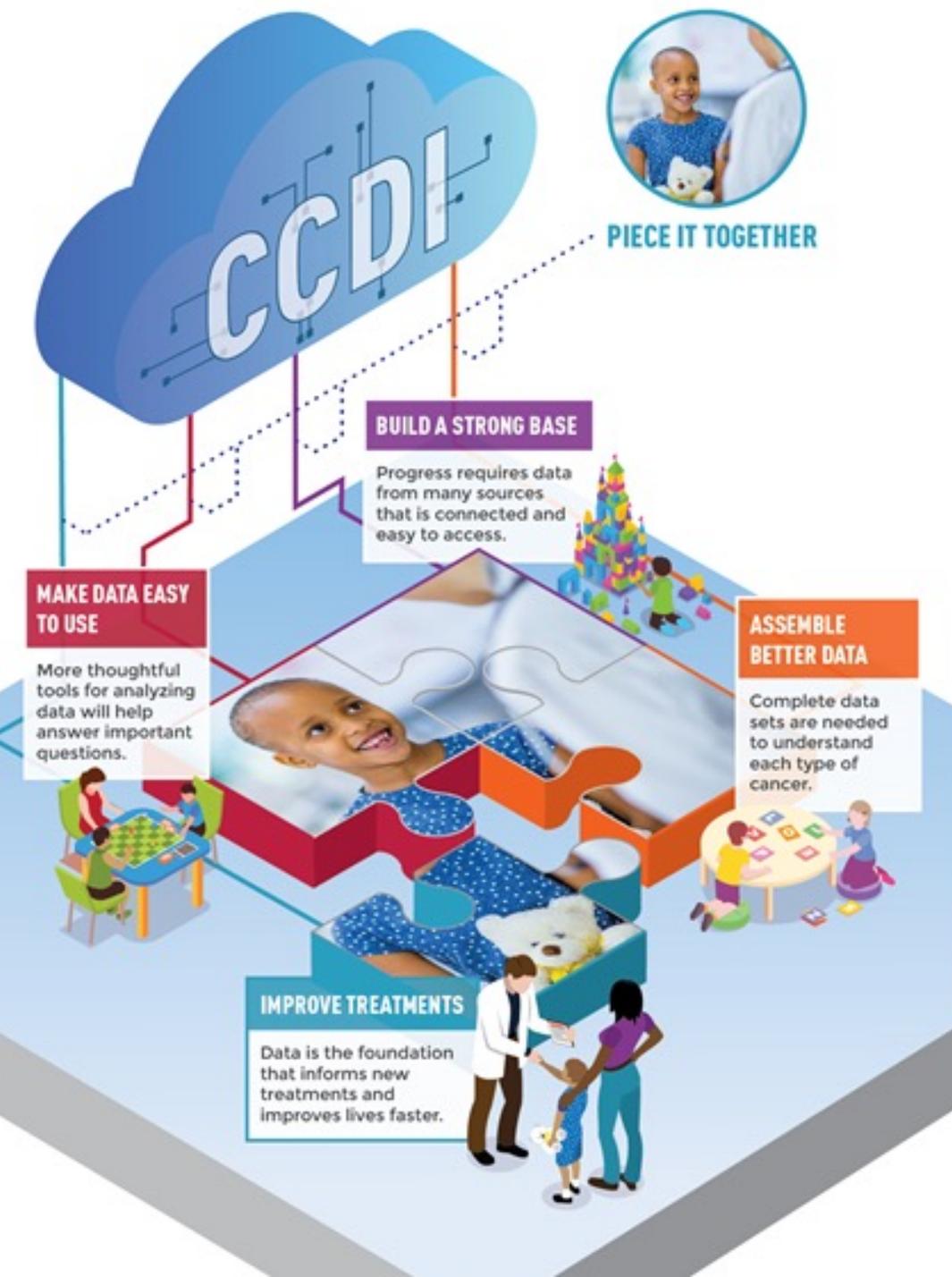
Distinction Between Research & Clinical Data



Engaging Diverse Array of Stakeholders for Input



Potential Opportunities for Transformative Discoveries



Using data to achieve the goals of CCDI

Piece it together: CCDI is completing the puzzle to learn from and help reach **better treatments and outcomes** for children, teens, and young adults with cancer.

Build a strong base: Progress requires data from many sources that is connected and easy to access.

Make data easy to use: More thoughtful tools for analyzing data will help answer important questions.

Assemble better data: Complete data sets are needed to understand each type of cancer.

Improve treatments: Data is the foundation that informs new treatments and improves lives faster.

Featured CCDI Accomplishments

- Progress on the CCDI Data Ecosystem
 - CCDI National Childhood Cancer Registry
 - CCDI Childhood Cancer Data Catalog
- CCDI Molecular Characterization Initiative

Progress on the CCDI Data Ecosystem

CCDI Data Ecosystem

- The CCDI Data Ecosystem is a connected network of tools and resources that will bring together clinical, research, and registry data on children, adolescents, and young adults (AYAs) with cancer from separate collections of data
- It will also provide tools to use the data in new ways
- Users will be able to access the ecosystem through a centralized portal

CCDI National Childhood Cancer Registry (NCCR)

- Rapidly growing public health statistic data resource
- Collects data from children and AYAs with childhood cancer, regardless of where they receive care
- Enhances access to, and use of, childhood cancer and survivorship data
- Allows researchers to answer important questions need to improve outcomes and track clinical trial participation

The screenshot shows the homepage of the National Childhood Cancer Registry Explorer. At the top, the NIH logo is followed by the text 'NATIONAL CANCER INSTITUTE Childhood Cancer Data Initiative National Childhood Cancer Registry Explorer'. Below this is a purple header bar with the text 'Statistics for cancers in children, adolescents, and young adults'. A dark navigation bar contains the links 'HOME', 'APPLICATION', 'ABOUT', and 'HELP'. The main content area has a dark blue background. On the left, under the heading 'Explore Our Statistics', there is a paragraph describing the tool's capabilities and a purple 'Get Started' button with an external link icon. On the right, a white box titled 'With NCCR*Explorer, you can...' lists three features: 'Create custom graphs and tables', 'Download data and images', and 'Share links to results', each with a corresponding icon.

CCDI National Childhood Cancer Registry

Initial Registry Participation (70% of US childhood cancers)

7 NPCR Registries

Florida
Illinois
New Jersey
Ohio
Pennsylvania
Tennessee
Texas

2020 - submission of de-identified NAACCR data in NCCR

2021 - full registry submission with PII to DMS*Lite as a repository for linkages and submission to the NCCR

SEER Registries

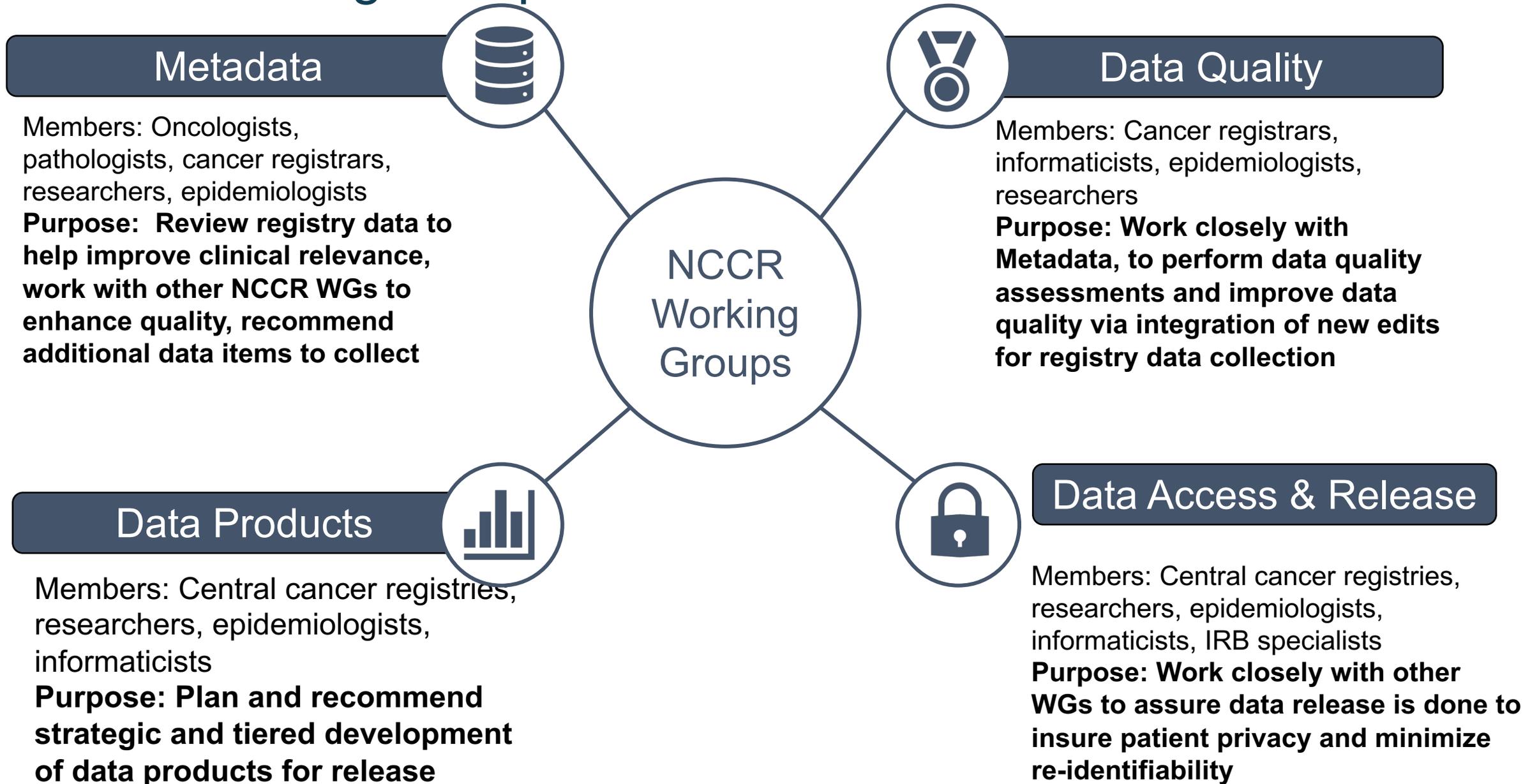
Georgia
Los Angeles
Greater CA
Greater Bay Area
Iowa
Connecticut
Kentucky
Louisiana
Seattle
Idaho
New York
Massachusetts

SEER will contractually require submission to the NCCR

Goal

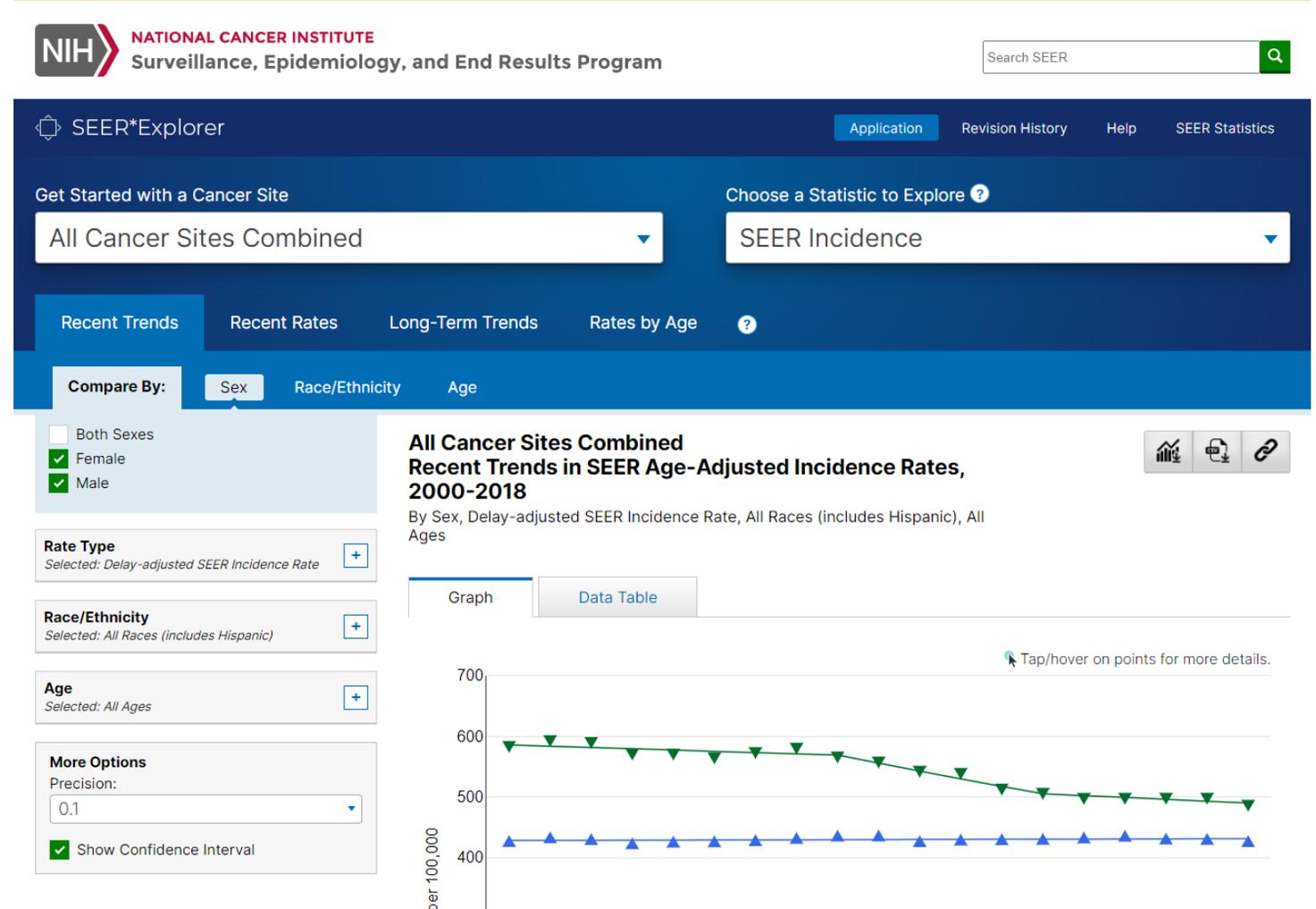
100%
coverage of
all pediatric
patients over
the next few
years

NCCR Working Groups



NCCR*Explorer

- V1 released November 2021
- 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



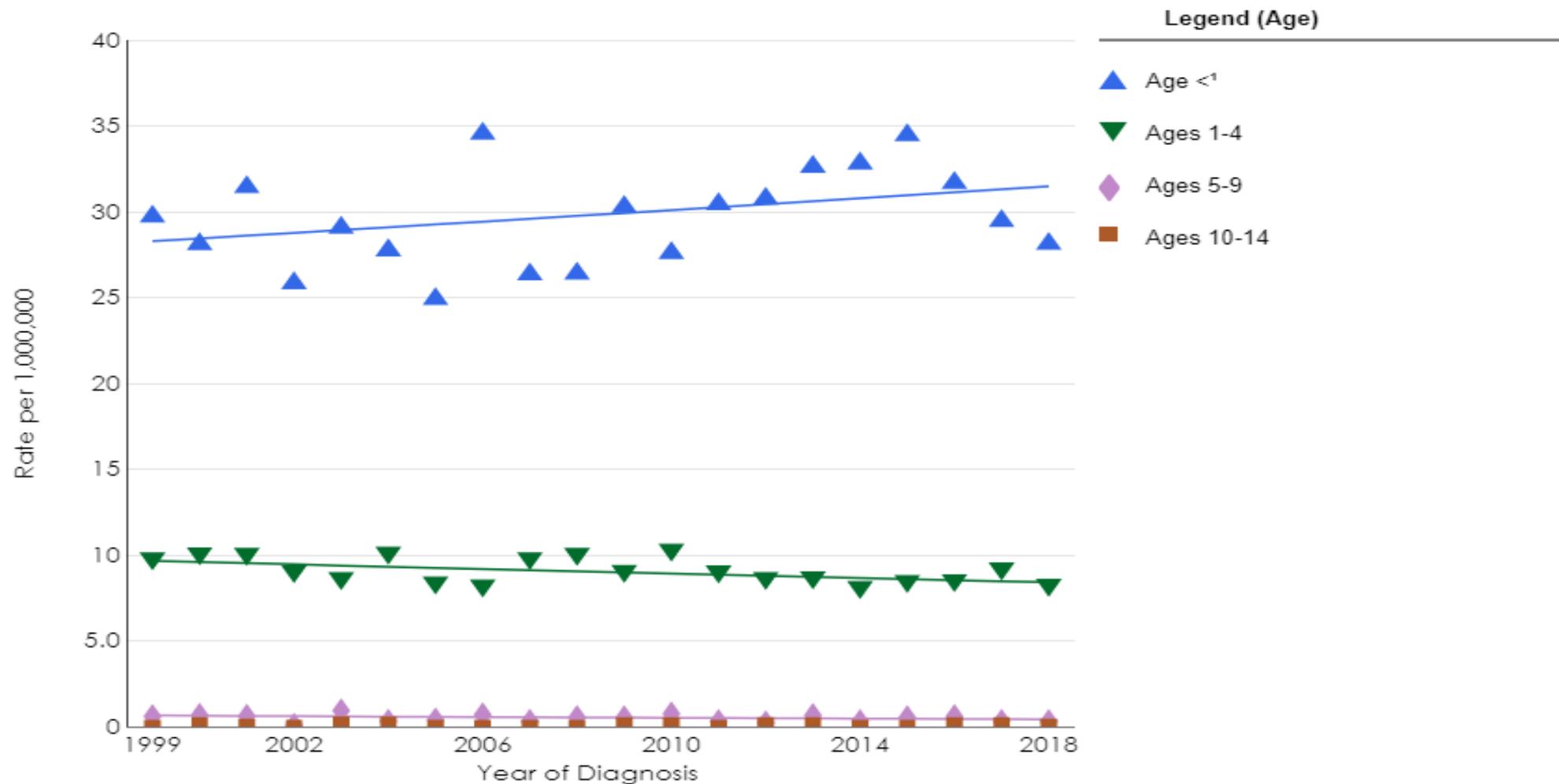
nccrexplorer.ccdi.cancer.gov

V. Retinoblastoma

Trends in Age-Adjusted Incidence Rates, 1999-2018

By Age, Both Sexes, All Races

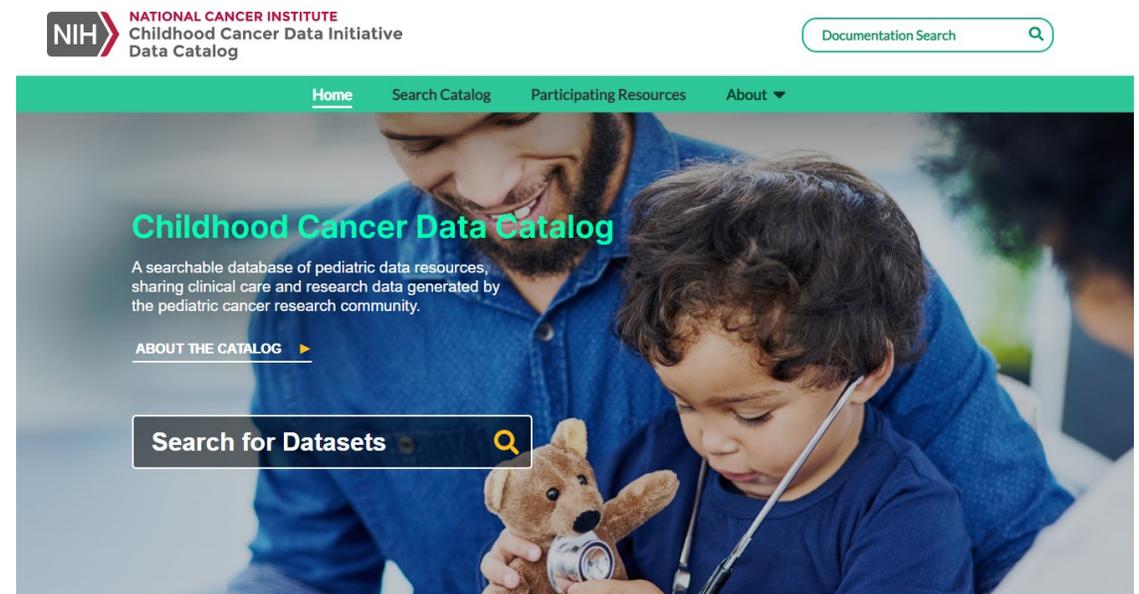
NCCR Registries, 23 U.S. Cancer registries that represent 66% of all U.S. children, adolescents, and young adults



CCDI Childhood Cancer Data Catalog

- An inventory of childhood cancer databases
- Includes repositories, registries, data commons, websites, and catalogs that manage and refer to data
- Each resource page includes a summary description and links to access the data
- Makes it easier for researchers to find data that could help them with their work

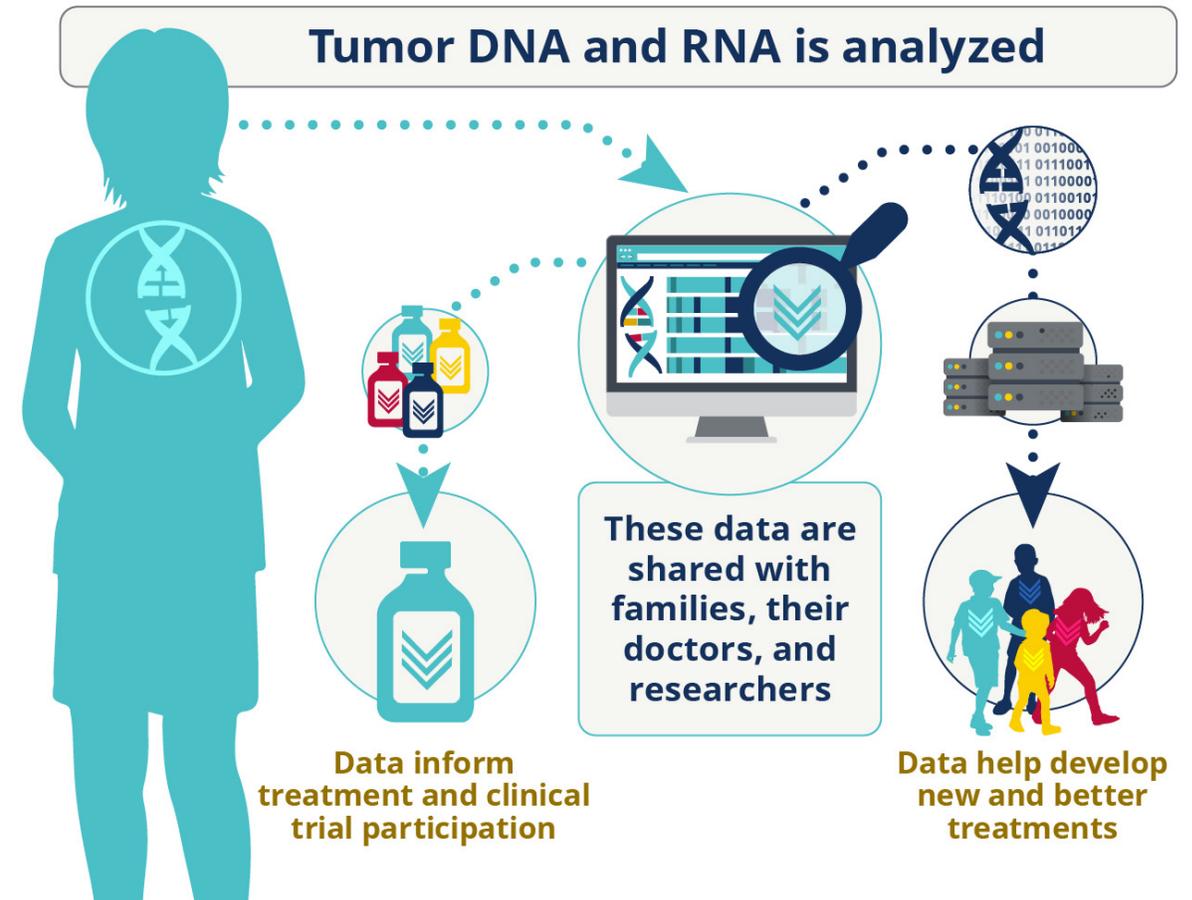
datacatalog.ccdi.cancer.gov



CCDI Molecular Characterization Initiative

CCDI Molecular Characterization Initiative (MCI)

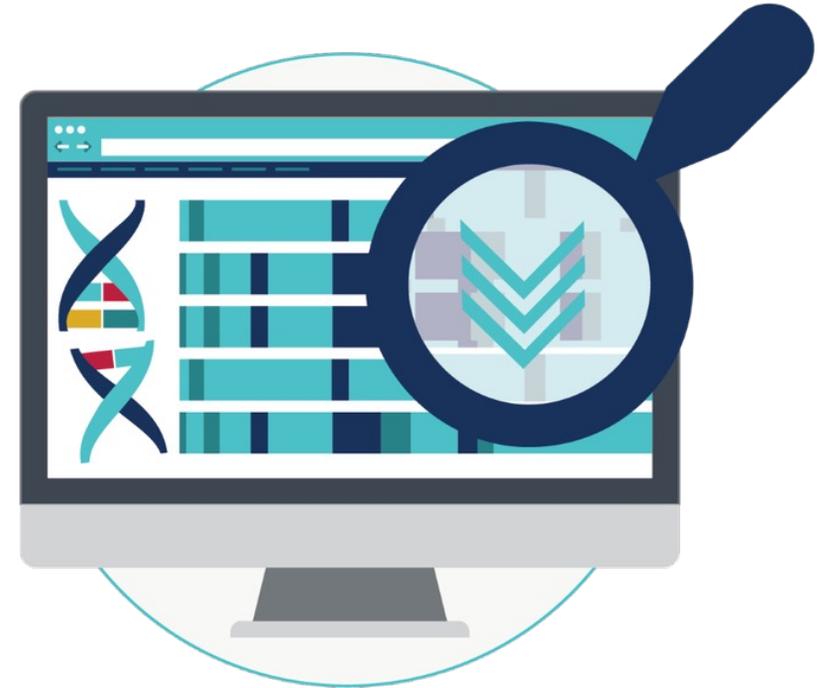
- A partnership between NCI and COG PEC
- Provides state-of-the-art molecular characterization at the time of diagnosis to inform the best and most appropriate treatment
- Results returned to participants and treating physicians within 21 days
- Remaining samples will be stored in a biobank for future research



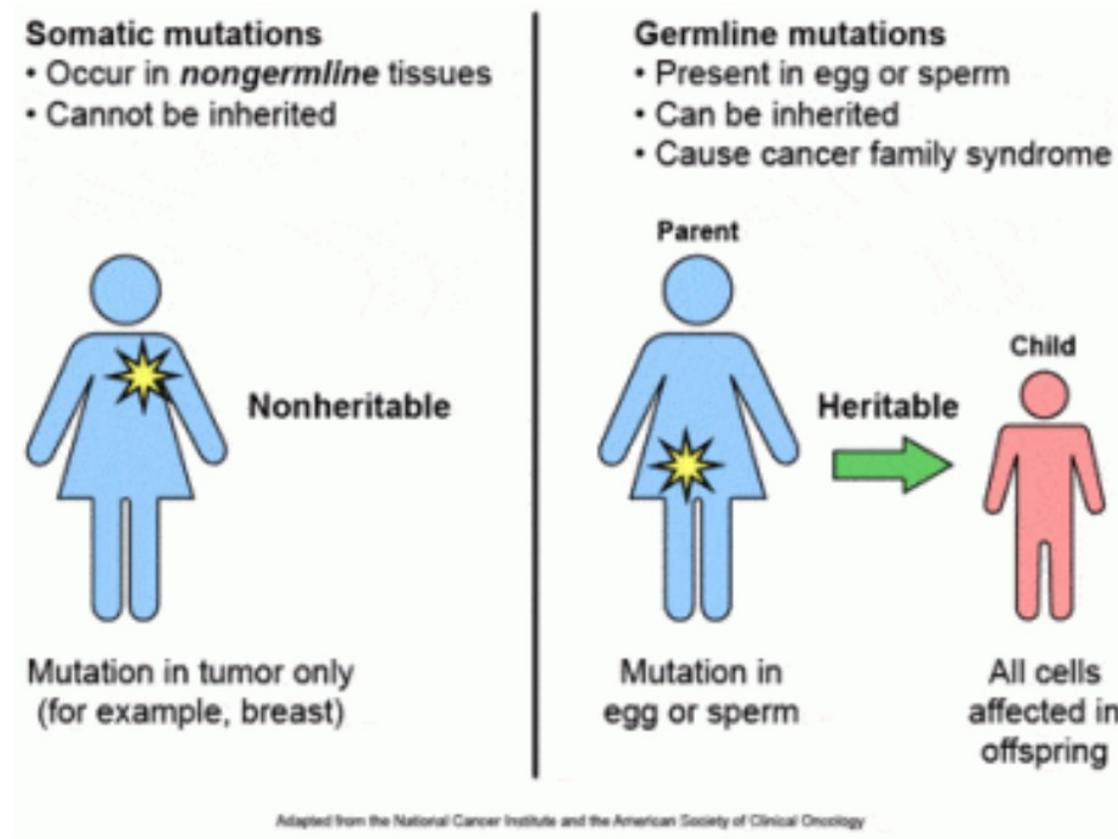
cancer.gov/CCDI-molecular

What Is Molecular Characterization?

- Uses multiple types of lab tests to learn more about tumor DNA, RNA, and proteins—to see what may be causing or driving a cancer
- Improves understanding of risk and susceptibility in patients and survivors in regards to:
 - Germline genetic susceptibility
 - Tumor classification
 - Treatments (proton therapy and adverse events)



What MCI Looks at: Blood and Tumor Changes



- The initiative looks at blood (germline) and tumor (somatic) sources
- This allows identification of inherited tumor predisposition

Participation in the Molecular Characterization Initiative

- **Participant must be:**

- Child or AYA 25 years old or younger
- Newly diagnosed with no prior cancer treatment history
- Diagnosed with a central nervous system tumor (tumors of the brain and spine)
- Obtaining care at Children's Oncology Group-affiliated hospital
- Enroll on PEC

- **The initiative will expand in 2022 and 2023 to include:**

- Other cancer types (soft tissue sarcomas and rare tumors), relapse cancers
- Additional hospitals and cancer centers

Next Steps for CCDI

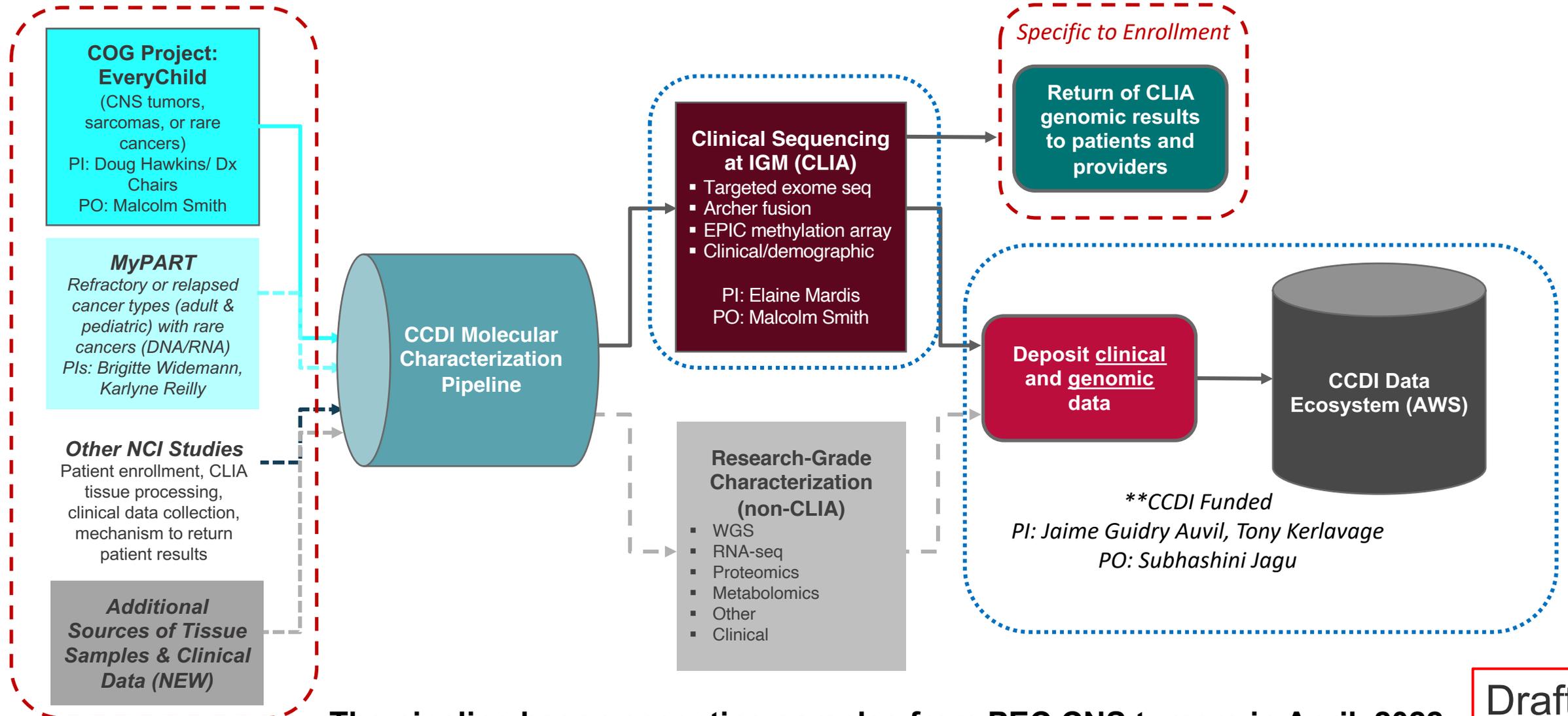
Next Steps

- The Molecular Characterization Initiative will expand in 2022 and 2023 to include:
 - Other cancer types (soft tissue sarcomas and rare tumors), relapsed cancers
 - Additional hospitals and cancer centers
 - Longitudinal cohort studies
- The CCDI Data Ecosystem will grow, with:
 - New data becoming available
 - The launch of the Molecular Targets Platform: a tool that provides information about molecules involved in the growth and spread of cancer cells (molecular targets) that specifically affect childhood cancers

CCDI Molecular Characterization Initiative: Clinical Pipeline

Protocol Enrollment

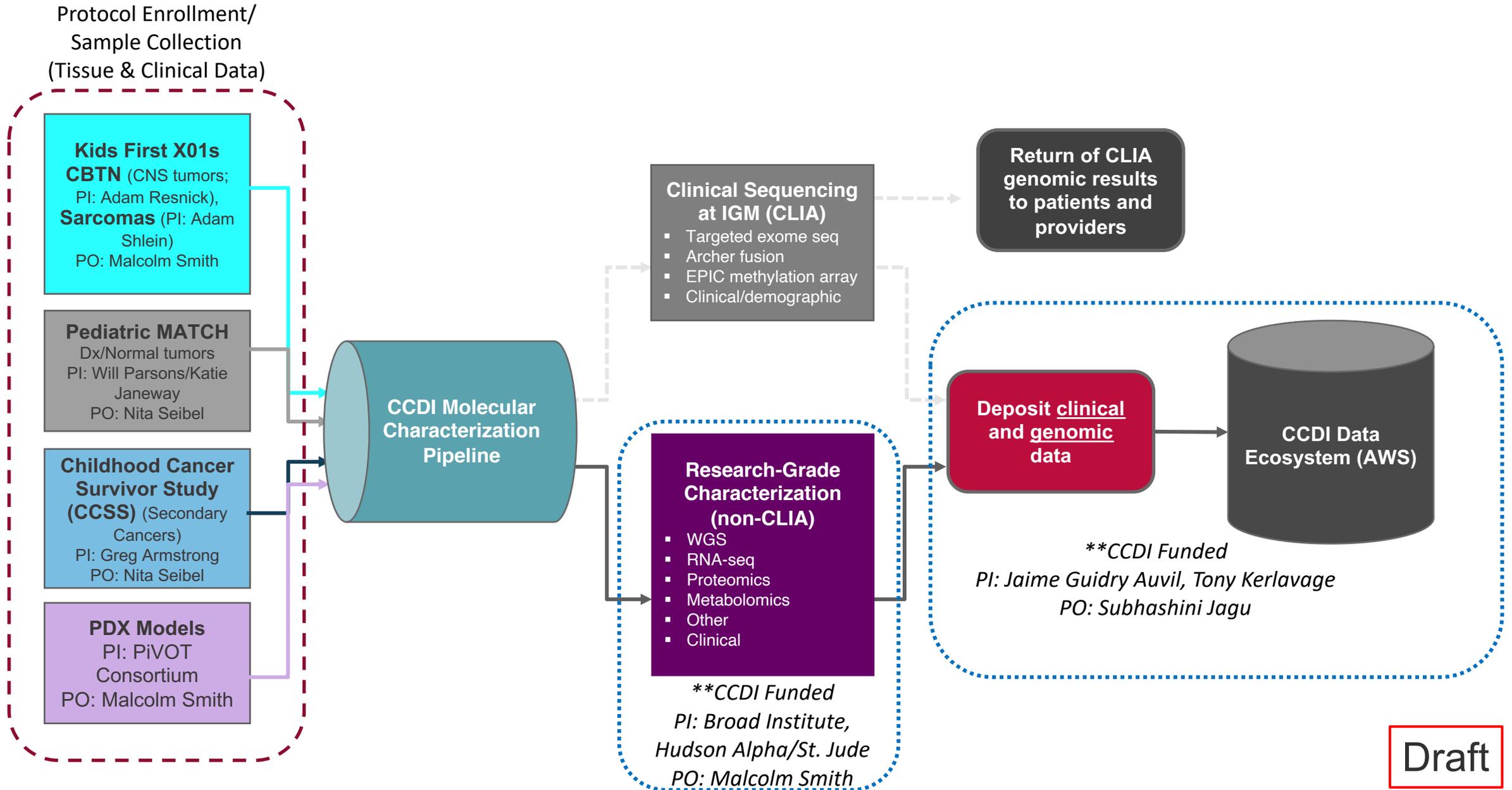
(Goal: determine best strategy to treat & learn from each child)



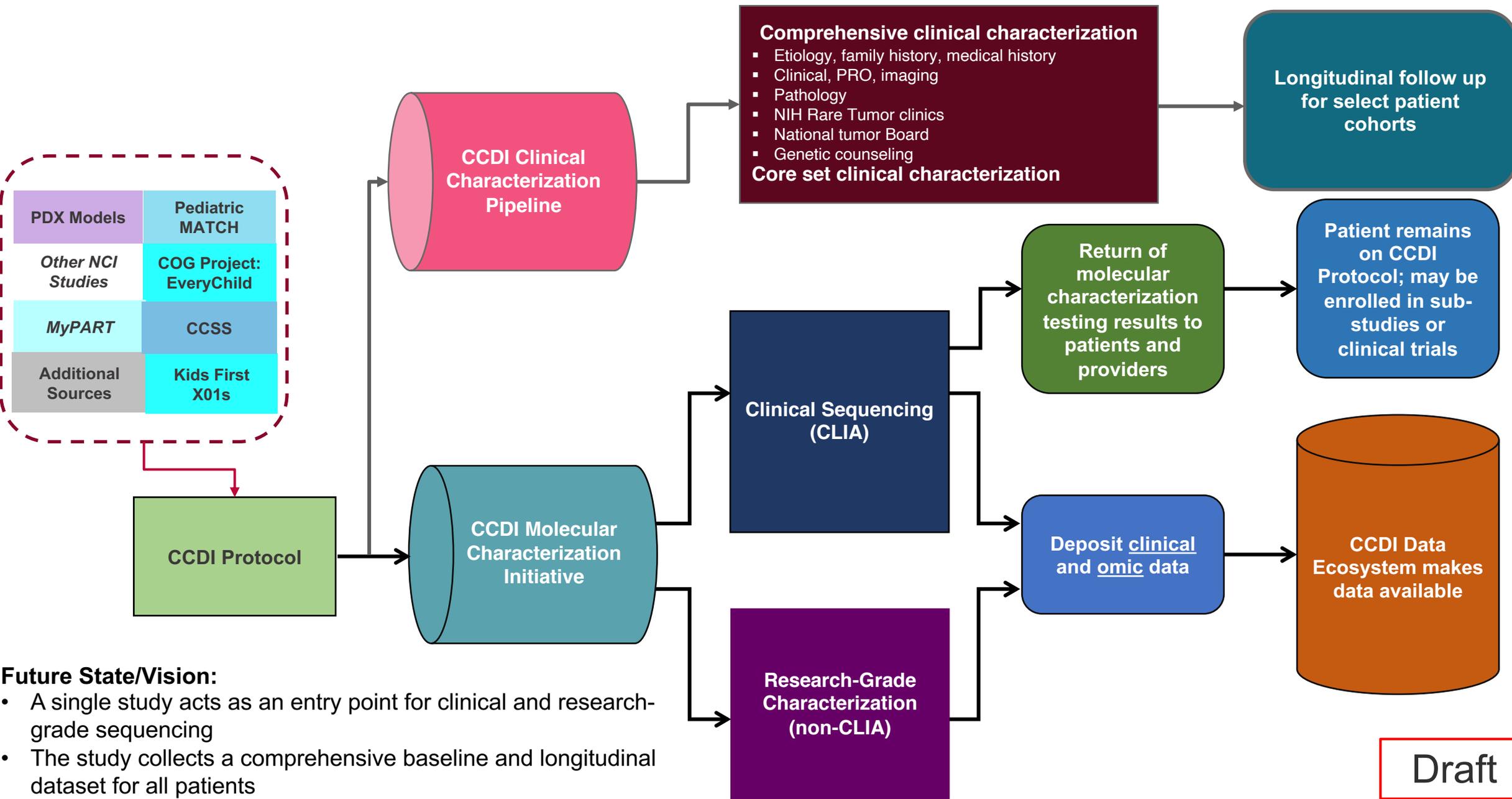
The pipeline began accepting samples from PEC CNS tumors in April, 2022

Draft

CCDI Molecular Characterization Initiative: Research Pipeline



CCDI MCI: Clinical & Research Pipeline and & Clinical Characterization



Future State/Vision:

- A single study acts as an entry point for clinical and research-grade sequencing
- The study collects a comprehensive baseline and longitudinal dataset for all patients

Draft

Upcoming CCDI Communication and Working Group Activities

- Web page refresh
- Increased social media use, #Data4ChildhoodCancer
- Monthly email newsletter
 - Progress updates
 - Stories from the community
 - Opportunities to engage
- Working groups are assembling and prioritizing recommendations for future planning

Update on Funding Opportunities

- CCDI will host a series of workshops focused on critical priorities identified in the wider pediatric/AYA cancer community that NCI will use to help hone upcoming concept building for the next phase of CCDI

Funding Opportunity Process



Based on the feedback, NCI identifies a priority that the government could fund. This is not revealed to or discussed with anyone outside the federal government.

No specific timeline

Priority Identified by NCI



RFA is released to the community for competition. Federal staff may only discuss this with external community members in an open, structured forum.

Opportunity Issued



Community Feedback – Open Workshops or Meetings

Open discussions about needs and priorities of the research community. No specific activity or implementation approach is discussed. **No specific timeline.**



Concept Development

Internal, federal staff-only team works to develop the concept and funding mechanism. This is not revealed to or discussed with anyone outside of the federal government. **This can take anywhere from 8 – 24 months.**



Opportunity Awarded

NCI reviews proposals and makes awards. This can only be discussed with the community after award is made, contracting is in place, and funding has occurred. **1 – 3 months**

Sign up for CCDI updates at: cancer.gov/CCDI

Get in touch with NCI's Office of Advocacy Relations

advocacy.cancer.gov

NCIadvocacy@nih.gov

[@NCIadvocacy](#)

Thank you to the CCDI Engagement Committee and the childhood cancer community for helping shape CCDI and move it forward!



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