



An Introduction to the National Childhood Cancer Registry

North American Association of Central Cancer Registries
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Last year President Trump proposed

- \$50 million per year for 10 years
- to **speed progress for childhood and adolescent and young adult (AYA) cancer research.**

NCI is leading the **Childhood Cancer Data Initiative** (CCDI)

- the proposed federal investment to collect, analyze and share data to address the burden of cancer in children and AYAs.

CCDI Symposium (July 2019)

- More than 250 stakeholders from
 - ✓ Scientific
 - ✓ Academia
 - ✓ Government
 - ✓ Industry
 - ✓ Advocacy
 - ✓ Additional 700 who watched via videocast



Four breakout groups

- Prioritizing scientific and clinical research data needs for therapeutic progress
- Creating meaningful datasets for clinical care and associated research progress
- Infrastructure to enable federation among pediatric data repositories
- Development of tools and methods to extract knowledge from data

Infrastructure to enable federation among pediatric data repositories

- Develop better ways to collect and store multiple types of research and clinical data for investigators and clinicians to use. Ideally, data repositories will include comprehensive and standardized patient information that covers an extensive period of time on a range of omics (such as genomics, proteomics, and metabolomics), imaging, pathology, side effects, and patient- and caregiver-reported outcomes.
- Build a federated data framework; an infrastructure that connects multiple existing and new data repositories and systems and offers software tools for analyzing and sharing data.

*Putting these two pieces together—**better data collection** and **interconnected data repositories**—would create a cancer data ecosystem for childhood and AYA cancers that ensures data are findable and usable in a meaningful way.*

The next day back in LA, following the CCDI Symposium...

- Dennis and Amie drafted a 2-page suggestion on how to create a National Childhood Cancer Registry (NCCR) for consideration by CCDI
- National Cancer Institute is funding the NCCR working with



Goal: To create a data system comprising population-based data on pediatric cancer patients from across the US from dozens of existing data sources

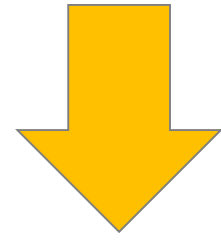
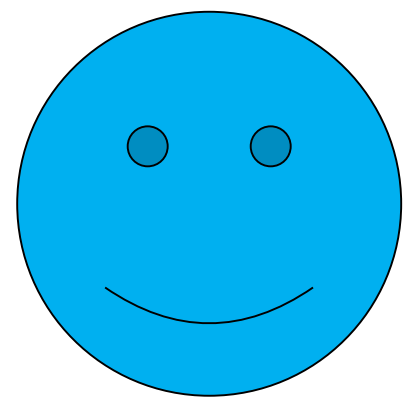
Aims

Build a base infrastructure for the NCCR including:

- Consolidated childhood cancer reports from population-based registries
- Supplemental data from unique data sources
- Provide high quality data by developing and utilizing automated and manual processes to monitor and assess data quality
- Develop standardized processes for data access and utilization by research investigators
- Maintain a sustainable infrastructure by developing administrative and governance plans



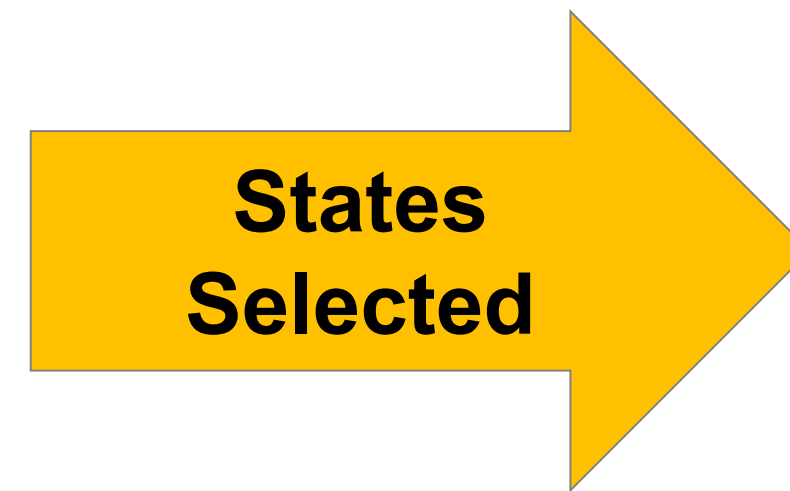
Building Upon the Virtual Pooled Registry – Cancer Linkage System (VPR)



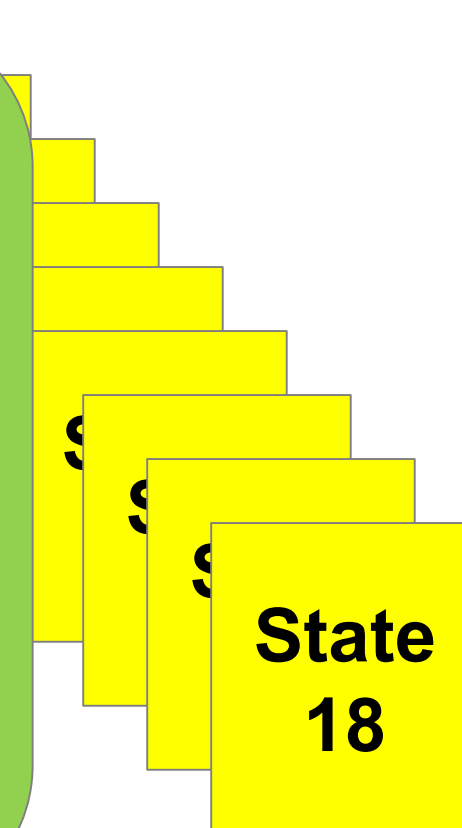
**Individual-level
data on
matched cases**

PHASE I: Initial Linkage & Counts

- Phase I application
- Single study file
- Single linkage software and standard configuration
- Aggregate match counts



**Linkage performed behind each
registry's firewall within 2 ½ weeks
using an annual registry linkage file**



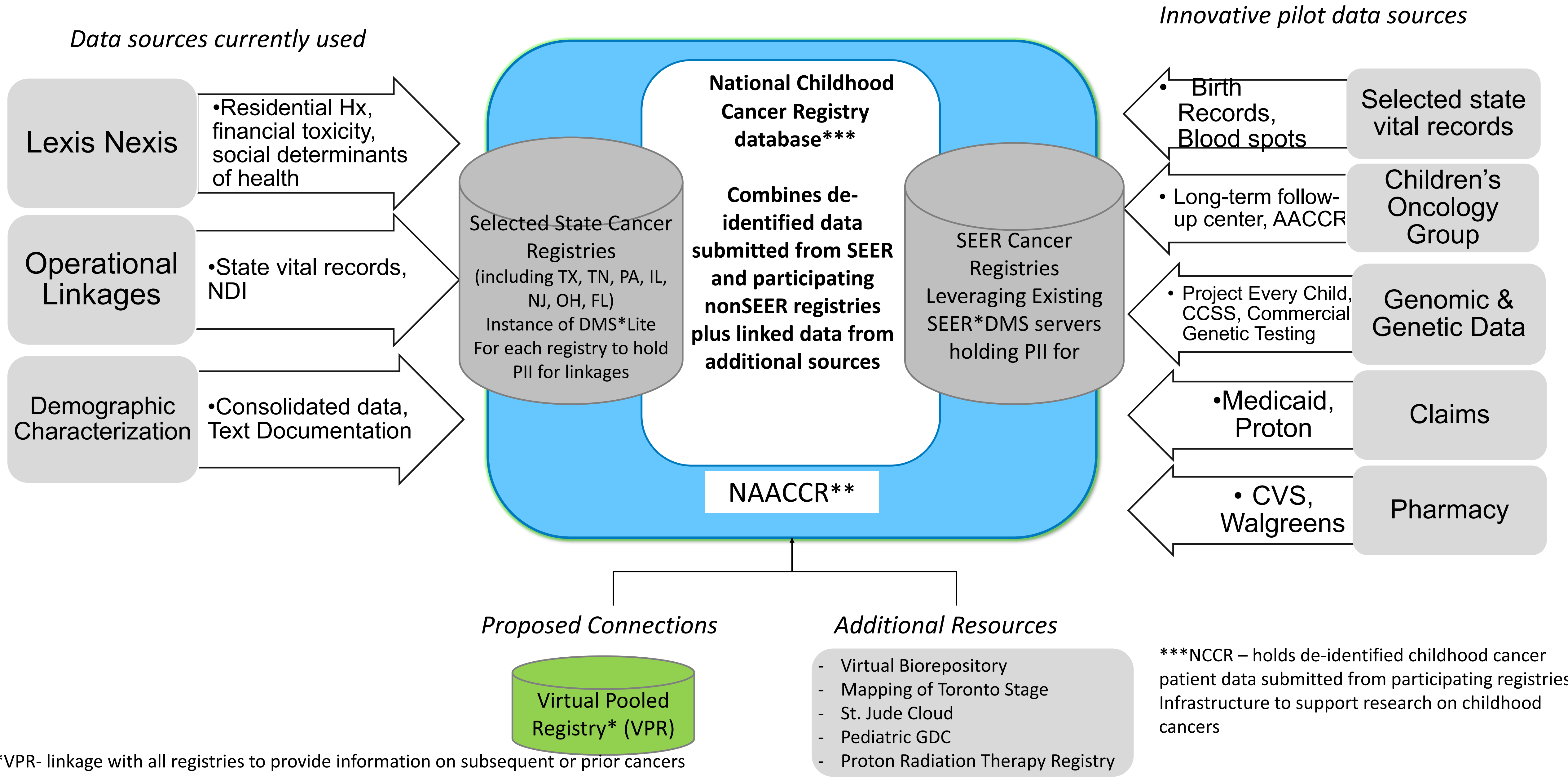
PHASE II: Request for Individual- Level Data

- Streamlined application process for individual-level data on matches using:
 - 1.) Templated IRB/Registry Application
 - OR
 - 2.) Central IRB Review
- Data entry and monitoring of registry/IRB approval, due dates, and requirements
- Workflow notifications and reminders



So how will it work?

Conceptual Framework: National Childhood Cancer Registry



*VPR- linkage with all registries to provide information on subsequent or prior cancers

** NAACCR is the coordinating center – does not hold or access data.

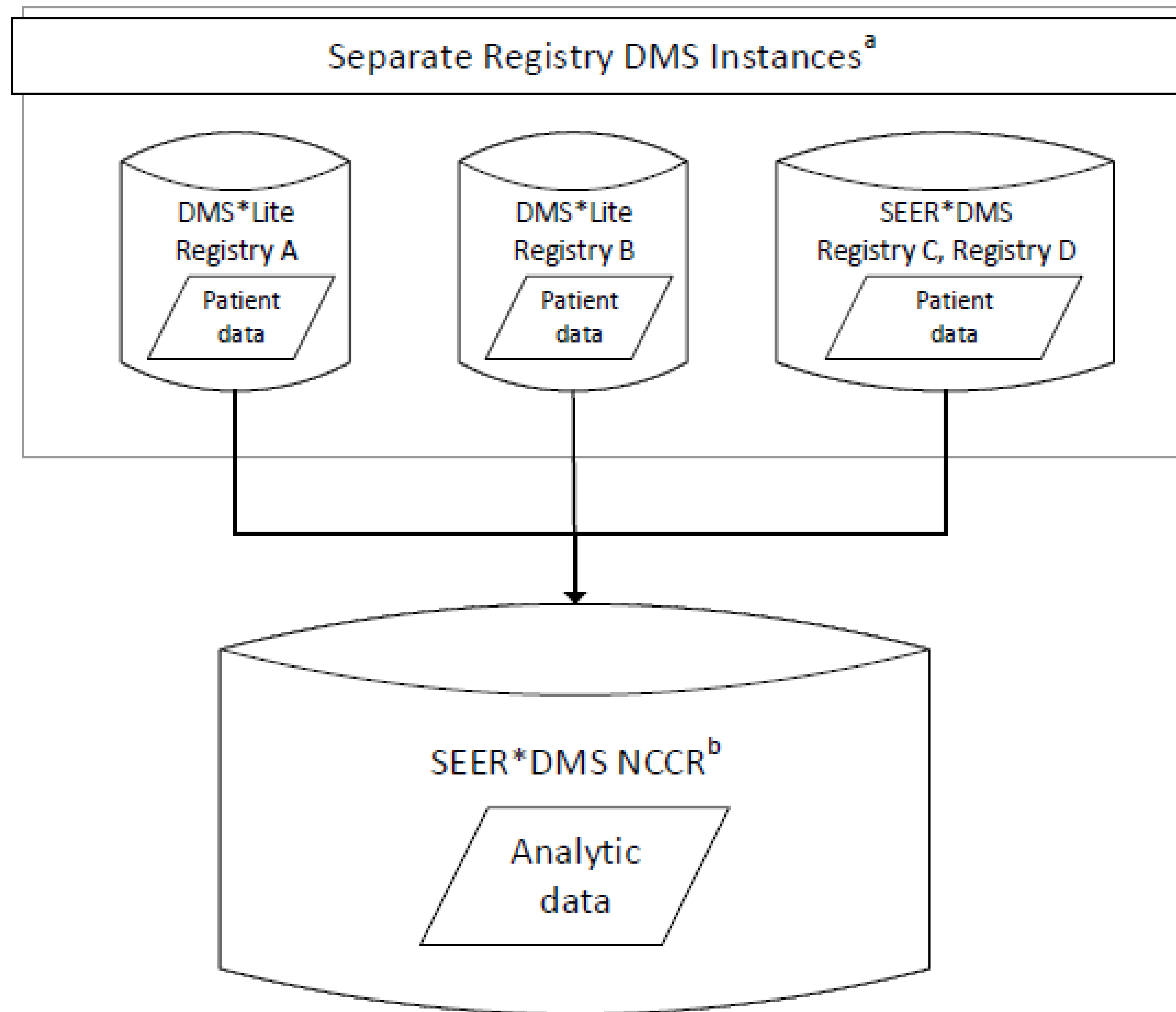


Data storage?

Agreements

IMS amendment
for SEER*DMS
registries

DUAs with non-
SEER*DMS
registries



Access

Full Access:
IMS

Registry will
have full access
to their own
data

Researchers &
NCCR staff with
appropriate
DUA and/or
IRB if necessary

^a NCCR data for each registry will be stored in either the existing SEER*DMS Instance or, for those registries not currently on SEER*DMS, in an instance of DMS*Lite

^b SEER*DMS NCCR will include the de-identified registry data.

Work in Progress

- Build the base structure
- Develop administrative and governance plan
- Develop data access and utilization processes

NAACCR Working Groups

1. Meta Data - Assure consistency across coding – initial focus on mapping histologies, identifying specific cancers that may need further assessment (e.g. fibrolamellar hepatica).
2. Data Access - Develop the policies, procedures and infrastructure to support efficient, confidential and secure data submission, access and release/use for the NCCR.
3. Data Products - Comprehensively identify the data utilization potential for the NCCR and develop innovative NCCR data output products that maximally utilizes NCCR data and meet the research needs of the pediatric and AYA cancer research community, while assuring compliance with all data use and protection requirements.
4. Genomics and Biospecimens - Identify sources of biospecimens and genomic and genetic data from NCCR patients and provide strategic planning for the cataloging, sharing, linking, integration and analysis through collaborations and partnerships.

Acknowledgements

Childhood Cancer Data Initiative

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Many enthusiastic subject matter experts