

Workshop #2

Interoperability

Session 3

Workshop #2 Session 3

Facilitators

Eric DURBIN - Kentucky Cancer Registry

Johanna GODERRE - US National Cancer Institute

Subthemes

- Are there data exchange layouts applicable to this project (or use cases that could be successfully modeled)?

Discussants



Stephanie HILL

USA

**North American
Association of Central
Cancer Registries (NAACCR)**
Associate Director



Paul SAULTIER

France

**AP-HM, Inserm,
LEA platform**
Associate professor



Cancer Registry Standardization in North America: Successes, Challenges, and Opportunities



Stephanie M. Hill, MPH, CTR
Associate Director, NAACCR

Cancer Registry Landscape in the U.S.



Hospital Registries

- State public health authority
- American College of Surgeons Commission on Cancer

Central/PB Registries

- National Cancer Institute (NCI) Surveillance, Epidemiology & End Results (SEER) Program
- Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR)

NAACCR Standards



Data
Standards & Data
Dictionary



Standard
Data
Edits



XML Data
Exchange
Standard



Electronic
Pathology
Laboratory
Reporting
Standards



Central
Registry
Operations
Standards

Standardization Challenges



Keeping pace with medicine



Managing change



Balancing stakeholder needs



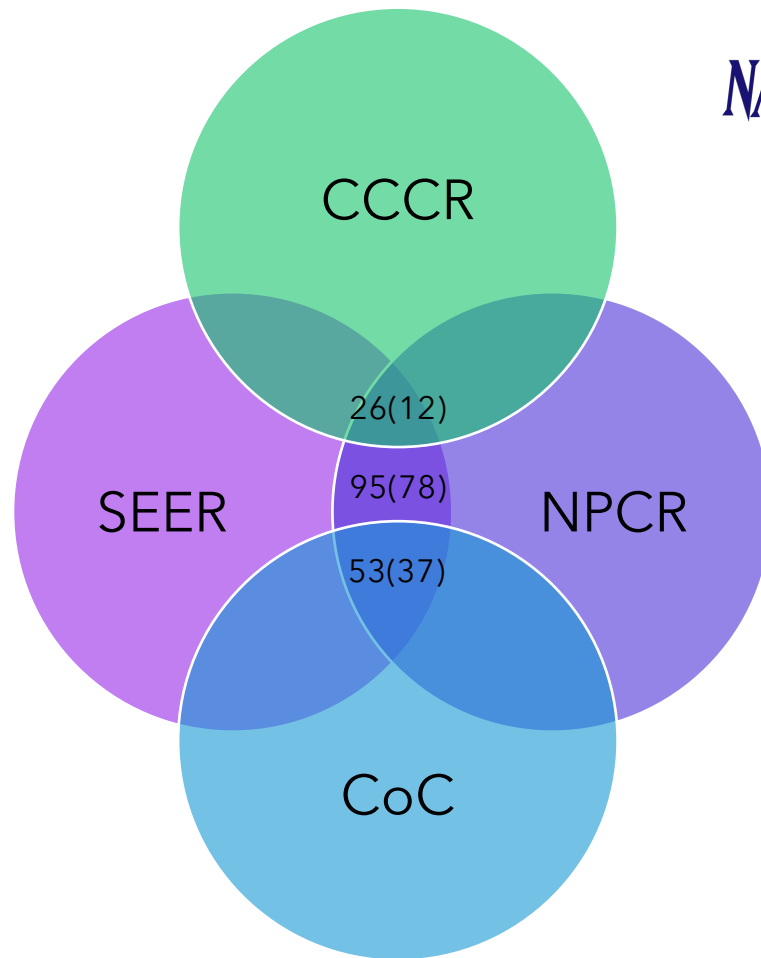
Interoperability with emerging data standards

Standardization and Variation

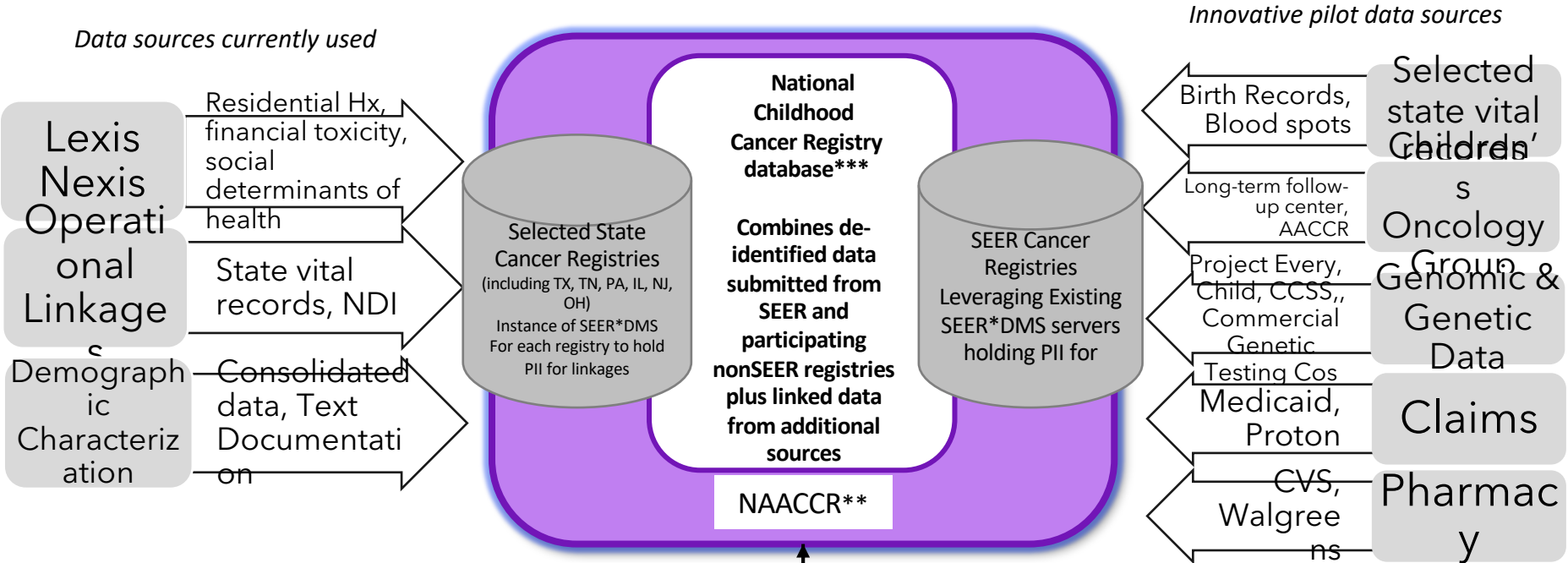


| Item # | Item Name | NPCR Collect | CoC Collect | SEER Collect | CCCR Collect | Source of Standard | Notes | Retired |
|--------|-----------------------------|--------------|-------------|--------------|--------------|--------------------|-------|---------|
| 368 | Census Block Grp 1970/80/90 | . | . | S | . | Census | | No |
| 369 | Census Tract Certainty 2020 | D | . | D | . | NAACCR | | No |
| 380 | Sequence Number--Central | R | . | R | D | SEER | | No |
| 390 | Date of Diagnosis | R | R | R | R | SEER/CoC | | No |
| 400 | Primary Site | R | R | R | R | SEER/CoC | | No |
| 410 | Laterality | R | R | R | R | SEER/CoC | | No |
| 420 | Histology (92-00) ICD-O-2 | RH | RH | RH | RH | SEER/CoC | | No |
| 430 | Behavior (92-00) ICD-O-2 | RH | RH | RH | RH | SEER/CoC | | No |
| 440 | Grade | RH | RH | RH | RH | SEER/CoC | | No |
| 441 | Grade Path Value | RH* | RH | RH | . | AJCC | | No |
| 442 | Ambiguous Terminology DX | . | RH | RH | . | SEER | | No |
| 443 | Date Conclusive DX | . | RH | RH | . | SEER | | No |
| 444 | Mult Tum Rpt as One Prim | . | RH | RH | . | SEER | | No |

Commonality



Standardization and the U.S. National Childhood Cancer Registry



*VPR- linkage with all registries to provide information on subsequent or prior cancers
 ** NAACCR is the coordinating center.
 ***NCCR – holds de-identified childhood cancer patient data submitted from participating registries.



Thank you

Stephanie M. Hill, MPH, CTR

shill@naaccr.org

<https://www.naaccr.org/>

<https://apps.naaccr.org/data-dictionary/>

The LEA project



Paul Saultier, MD, PhD

APHM – Pediatric Hematology, Immunology, and Oncology
Aix Marseille University – Inserm 1263 – C2VN

LEA project

Promoting and studying long-term health in survivors of childhood leukemia

lea

Hémopathies malignes
de l'enfant
et de l'adolescent



6,500+ included patients
treated from 1980

The program started in 2004



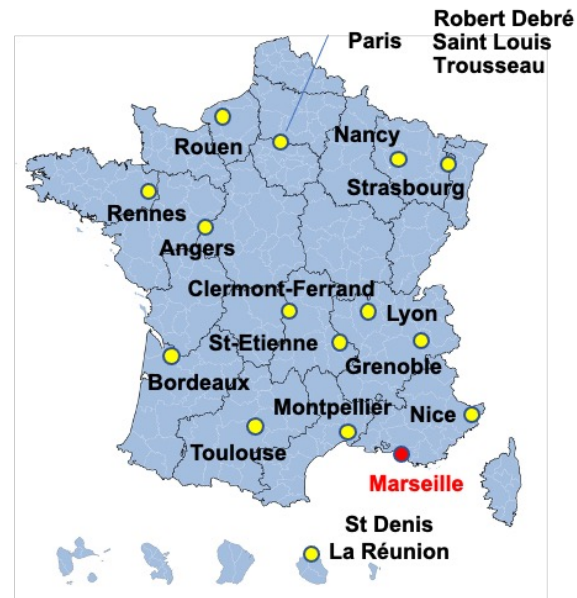
18 French Pediatric
Oncology Departments



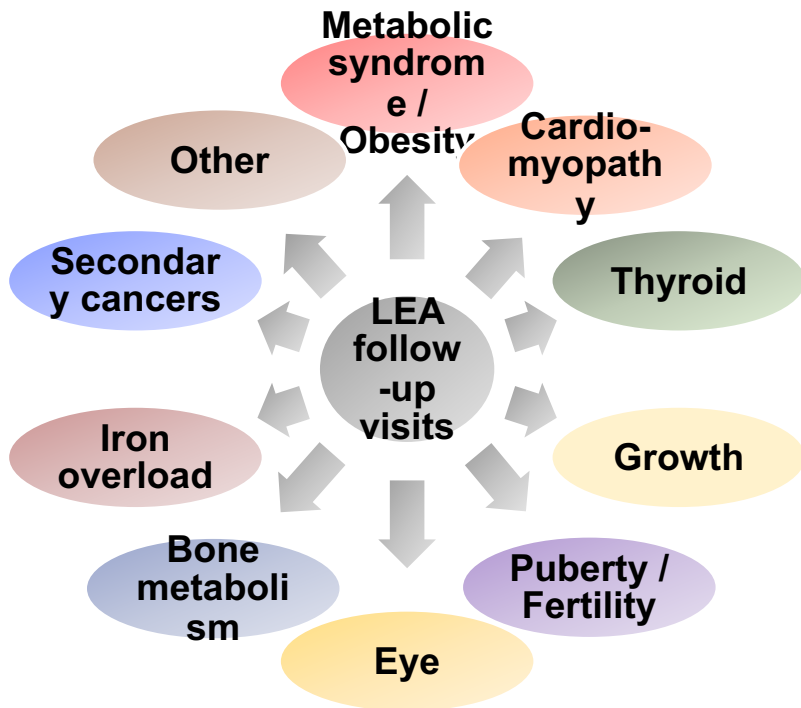
16,000+ dedicated
follow-up visits



Program started in 2004
500 k\$ / year (grants, charity)
40+ international publications



LEA Follow-Up Visits



Program of dedicated follow-up visits

Start 1 year after leukemia therapy and repeat /2-4 years thereafter

Prospective collection of data:

- Clinical examination
- Labs and imaging

Questionnaires (quality of life, socio-economic factors)

Metabolic syndrome in survivors of childhood leukemia

Major risk in patients who received total body irradiation (HSCT)

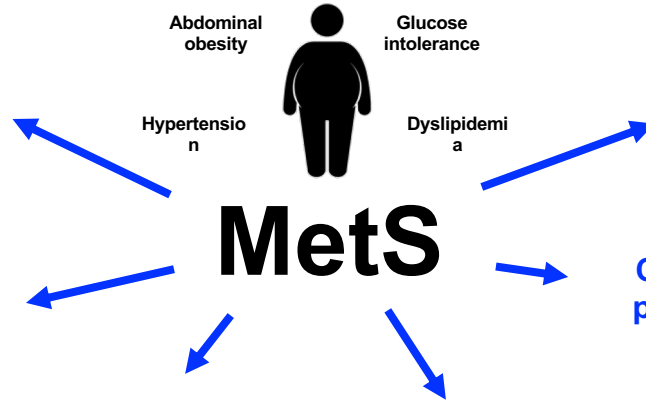
Oudin C et al. Blood. 2011 Apr 28;117(17):4442-8
Oudin C. et al., BMT, 2015, 50, 1438-44

Metabolic profile depends on the leukemia therapy (chemo vs CNS irr. vs TBI)

Oudin C, et al. Haematologica. 2018;103(4):645-654.

Total body irradiation induces lipodystrophy-like features

Visentin S et al. Endocr Connect. 2019;8(4):349-359.



(Moderately) increased risk in survivors treated with chemotherapy alone

Saultier P. et al., Haematologica, 2016, 101(12), 603-1610.

Cardiac and vascular risks are essential parameters for long-term surveillance of lower risk childhood acute leukemia survivors

Saultier P et al. Blood. 2022 Nov 15;140(Sup1):2187-9.
(ASH)

Limited efficacy of a physical activity and nutritional intervention

Visentin S et al. Manuscript in preparation

Future directions:

Innovative therapeutic approaches to mitigate cardiovascular risk

Better risk stratification: genetic predisposition

LEA biobank

Genetic predisposition to long-term complications



2000+ samples

Constitutional DNA (from PBMC or fibroblasts if HSCT), plasma

Dedicated research consortium

Genotyping + Exome sequencing

LEA governance regarding data sharing

Governance plan

Access to data is possible for researchers outside of the LEA consortium

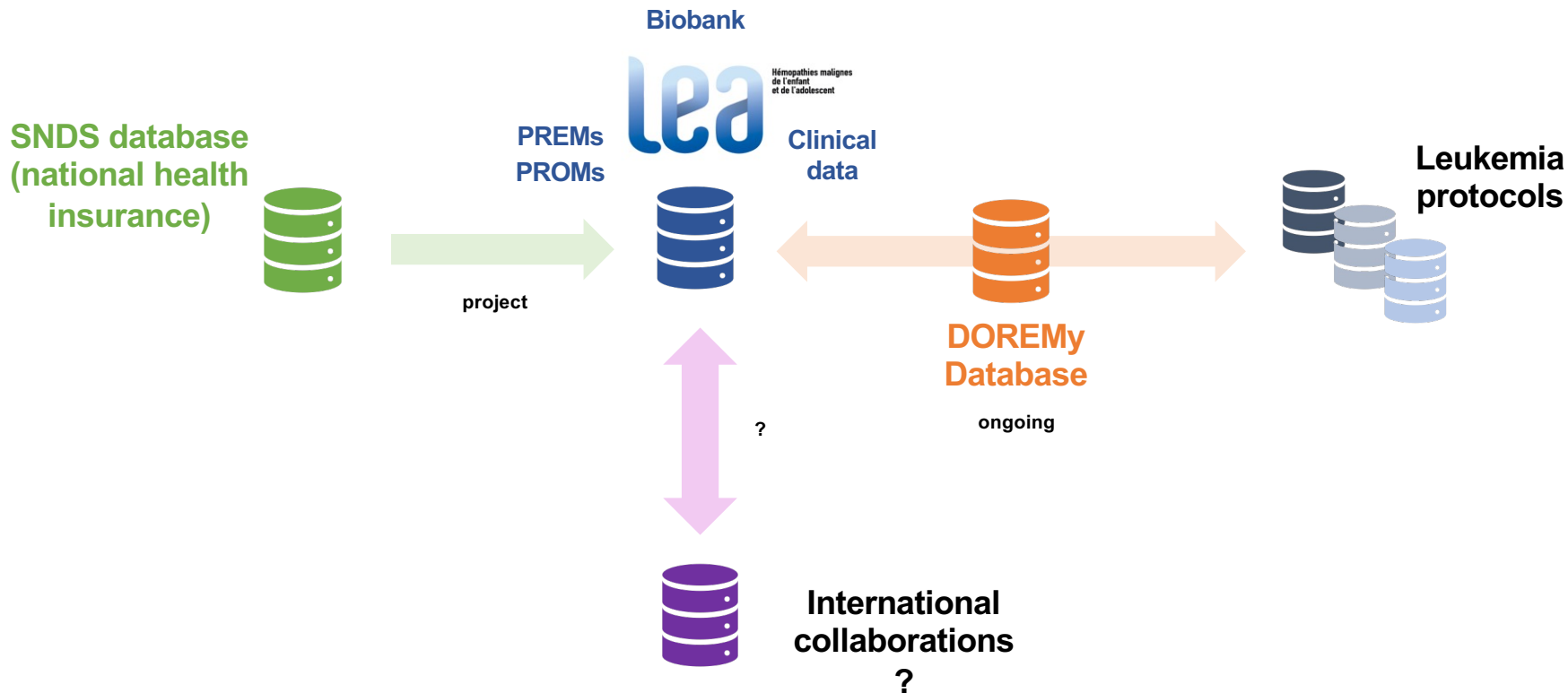
Rules to access to the data according to:

- Investigators from the LEA consortium *versus* outside the consortium
- Aggregated data *versus* individual data

Scientific council: evaluation of submitted requests

Intellectual property to be formalized

Interoperability in LEA project



Challenges

Definition of common governance rules for valorization of data

Authorization of health data hosting (GDPR)

Regulatory agreements for sharing research data

Centralization of data (EUR site if non-anonymized data)

Data portal access

Cost

Data heterogeneity (e.g. self-administered questionnaires vs. outpatient clinic with medical evaluation)

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LEA investigators: 100+ investigators / 18 centers

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Patients and families