



Challenges & Opportunities

Data Collection Methodologies & Technical Advances in Cancer Surveillance

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Strength: Data Element Standards

- Existing
 - CDC National Program of Cancer Registries
 - NCI SEER
 - AJCC Cancer Staging
 - NCDB
- Emerging
 - USCDI+ Cancer Registry Data Elements
 - Omics & Cancer Biology: HGVS

Task: Data Transformation & Transmission

- Data Representation & Harmonization
 - Structured data capture in EHRs
 - Reporting templates: Pathology synoptic reports *CAP & International Collaboration on Cancer Reporting*: SNOMED mapping
- Transmission Standards
 - NAACCR Vol 2 & 5
 - HL7 FHIR: CDC MedMorph
 - *State Cancer Registry capabilities*
 - *Bi-directional sharing*

Emergent properties & technologies

- Common Data Models: OMOP, mCODE, PCORI
- More nimble approaches
 - Generative AI
 - Pretrained with Neural Networks
 - Large Multi-Modal Models
 - Knowledge Graph Extensions: Retrieval-Augmented Generation
 - SDOH: U.S. Census, OSHA, NOAA
- Data Science, Machine Learning Algorithms
 - Quality & Value
 - Core part of the Learning Health System

Motivation for adoption of new approaches

- External Regulatory
 - Meaningful Use
 - Lower bar
 - Slowed innovation
 - California Cancer Data Modernization
 - Lower bar
 - Unfunded mandate
- Internal
 - If you build it...
 - ...reuse data for institutional priorities
 - ... will enable strategic partnerships
 - CCC 19
 - CodeX
 - University of Florida

Data Architecture for Learning Health System

Real World Evidence Outcomes & Value-Based

Payers
Life Sciences
Pharma
FDA
PCORI

Cancer Registries

State DPH-CDC
NCI SEER
ACS NCDB
ASCO QOPI
CIBMTR

Quadruple Aim

Patient Experience
Population Health
Affordability
Clinician Health

Strategic Partnerships

Universities
Tech Companies
Healthcare Companies

