TRANSMISSION TO CANCER REGISTRIES
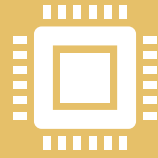
California Cancer Registry
Chronic Disease Surveillance and Research Branch
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Current Situation

Many individual state registries and programs attempting to target direct electronic data

Very little collaboration outside of specific domains such as cancer

All programs targeting the same institutions

Program specific data exchange standards

Result is multiple priorities put on the reporting entities, most of which do not get prioritized high enough for near term action, reporting entity resolves to meet only the lowest common denominator if they do implement

Current Gaps

- Availability of high-quality primary data from all reporting entities
  - *Discrete data must be created by someone*
    - Need to address "who" can and will do this work
  - *Target Primary Core data*
    - Patient ID, Demographics, Diagnosis
    - Do not allow "null values"
      - *Null Values result in data that is very difficult to process or is unusable*
    - Reporting entities must conform to data definitions and standards
      - *Leverage USCDI*
- Primary data profile can be used by all programs
  - *Supplementary (program specific) data can also be contained within any report*
- Incentives for healthcare entities to meet a higher standard

How do we make things easier?

Program Collaboration

- *Public health programs across the country are targeting EMR/EHR data in some way*
  - Hundreds of programs talking to the same institutions, dealing with the same physician associations, working with the same vendors
    - *Every conversation includes Demographic data*
    - *Most conversations include Diagnosis data*
    - *Some conversations include Lab test data, Medications, Treatment, SDOH*
    - *Need Core, Common, Unique Data Profiling*

Electronic Exchange Harmonization

- *Where possible, standardize on electronic exchange*
  - Example: Cancer Pathology, Infectious Disease, and Parkinson's per common data format standards
    - *HL7 v2.5.1 ORU_R01*
    - *HL7 eICR*
    - Future goal: HL7 FHIR resources

How to make interfaces work

- Address the issue of data curation within healthcare institutions
  - *Discrete data is difficult to create, especially to a standard. Most reporting entities don't have the time and staff resources to create the data we ultimately want*
  - *Healthcare institutions have massive billing departments, but they do not have data coding departments. Public Health reporting is massively under funded.*

- Primary data profile which can be used by any program targeting direct electronic exchange
  - *Supplementary (program specific) data can also be contained within any report (i.e., pathology report can be a narrative attachment at minimum, hybrid inclusive of some discrete data, fully structured report)*

- Give financial support for vendor implementations
  - *Many health care entities still cannot afford to meet a higher standard*
  - *Needs to be some type of incentive for entities to meet a higher standard (i.e., initial implementation dollars, higher reimbursement dollars, ongoing support funding for upgrades)*

Recommendations

- Address the data curation issue: Start working with EHR/EMR vendors to embed workflows within the systems to enter and store discrete data

  - *Retrain the CTR workforce to work, at least partially, within the EHR/EMR workflows*

- Work with other public health entities to standardize on core data definitions and reporting standards

  - *Work towards a primary data profile which can be consumed efficiently*

- Incentivize healthcare institutions to meet a higher-level standard

Thank You

Questions?