SEER*DMS

Discussion Objectives

Where Structure Meets Science

Objectives

- Frame the discussion around the current and future needs for SEER*DMS
- SEER*DMS is the foundation for registry operational activities and future data driven efforts
- Understand the scientific initiatives that require integration
  - Current Landscape of New Data Sources
  - Current Needs for Data Quality
  - Advanced Methodologies and Techniques (i.e. NLP, ML)
- Work together to meet the needs of the registrar, technical advisor, scientist, and clinician communities

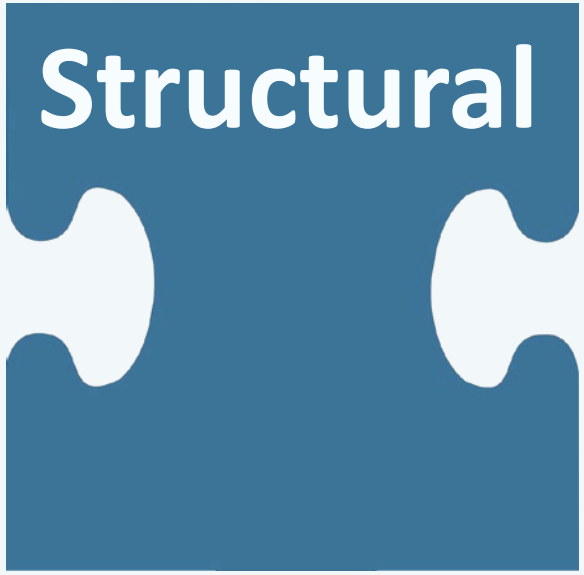
Questions We Are Asking

How do we plan for structural SEER*DMS changes as we expand our data linkages?

How do we come to understand what each individual registry is doing so that we can leverage these practices to develop SEER wide standards?

What data sources facilitate registry operations?

How do we internally develop a plan for SEER*DMS changes to help improve registry operations?



Database Structure
Multiple Data Feeds
Hardware Specifications
New Features
Algorithms

New Data Acquisitions
Enhance Treatment Data
Improve Extramural Resources
Empower Clinical and Epi Cancer Research
Innovation for Cancer Surveillance

SEER

Aims

Structural

Data Acquisitions & Linkages

- Example: Do we need to make changes to our server architecture?
- Example: Do we need to account for a new data formats in SEER*DMS? (Claims 837 format)

Data Quality

- Example: Do we need new edits, tools, processes in SEER*DMS to improve quality checks?

Scientific

Data Acquisitions & Linkages

- Example: Enhance treatment data through acquisition of oncology practice claims
- Example: Multiple linkage types allow better understanding of outcomes such as recurrence

Data Quality

- Example: PSA Quality Audit explored decimal point inconsistencies which impact research

Our Current Focus Areas

- Data Sources
  - Types:
    - Medical Claims
    - Pharmacy
    - Electronic Health Records
    - Radiology
    - Genomic
    - Radiation Oncology
    - Patient Generated Data
    - Supplementary Data (outside healthcare system)
- Data Quality
  - Studies to improve the quality and accuracy of SEER Data
    - PSA
    - Melanoma Tumor Depth
    - HPV

Registry Data Linkages Working Group

- Registry of the Future Session on Current and Future Data Sources
- Deliverables:

  In 3 months:

  ✓Everyone wants to join this Working Group ☺

  ✓Share our decision matrix tool for data linkage evaluation with committee and ask for addition input

  In 6 months:

  ✓Conduct a survey of registries around feasibility and best practices of data linkages

  ✓Focus on: legal, technical, qualitative, governance for a feasibility study of a single source

  In 12 months:

  ✓Conduct a feasibility study targeting a specific data source defined by the WG

  If you would like to join, please email Donna at donna.rivera@nih.gov

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SEER

Thank you!

"Here's a list of 100,000 warehouses full of data. I'd like you to condense them down to one meaningful warehouse."