

CI4CC - Spring 2017 Report Out

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2017 Spring CI4CC Conference Focus: Cancer Registries

- Important role of cancer registries in the national cancer data ecosystem
- Agenda highlighted current registry resources, infrastructures and best practices
- Establish forum for CI4CC and registry communities to share knowledge, ideas and establish new collaborations
- Intent is for cancer registries to realize their greatest potential for service to the national/international data ecosystem

Cancer Registries

- Widely recognized as a fundamental and essential source of cancer information
- Serve as definitive source of truth delineate patients, cancer diagnoses and outcomes
- Central cancer registries serve as state-mandated public health authorities which assimilate data from multiple sources ultimately provide long term outcomes of the cancer population
- US and Canadian registries follow a common data model and data standards maintained by stakeholders through the NAACCR (North American Association of Central Cancer Registries)
- Aim to provide a universal, standardized data collection infrastructure to allow the community to leverage registry data across the cancer center research sectors

Cancer Registries – Limitations and Opportunities

- Suffer from recognized limitations in provision of a wider, deeper and more timely data paradigm required by precision medicine initiatives
- Opportunities exist to address many limitations through informatics

Selected Topics

- ASCO CancerLinQ Update: George Komatsoulis, PhD
 - Allows organizations to get de-identified information (discovery set) from the entire cancer community
 - Vanderbilt, Univ. of Virginia etc. have signed on
 - Will open in Q1 2018
 - To gain access, center will need to go through discovery process
- Special Keynote: Matthew Trunnell, Chief Information Officer, VP of Information Technology, Fred Hutch Comprehensive Cancer Center
 - Establishment of a Data Commons for researchers
 - Inclusion of an Omics data commons
 - How to ensure various data ecosystems actively participate in effort? Internal grant incentives
 - What is the process to build this?

Selected Topics

- NCI SEER Registry Workshop Session- Chair: Lynne Penberthy, MD, MPH, National Cancer Institute Surveillance Research Program, DCCPS, NCI
 - Data Governance and I2B2
 - Equivalence vs. matching (Entity Resolution)
 - Registry matching initiatives
 - PCORI
 - Use of hash bundles for matching
 - Linking genetic testing to SEER data
 - SEER Syapse precision oncology registry

Selected Topics

- Demystifying Big Data and Machine Learning for Healthcare
 - Use of NoSQL and Data Lakes
- Use of E-path for rapid case ascertainment in real time (NLP)
- Bill AB2325 which mandates electronic reporting by Jan 2019
- FHIR (Fast Healthcare Interoperability Resources)
- Other sources of data: TCGA, ORIEN, LCMC (Lung Cancer Mutation Consortium)
- CTmatch4CC Initiative – Forte

Selected Topics

- Cancer Center Director's Keynote: Richard A. Van Etten, MD, PhD, Director, Chao Family Comprehensive Cancer Center, Professor of Medicine and Biological Chemistry. University of California, Irvine
 - Spoke about issues that currently exist
 - Software for membership, pubs, grants
 - Converting Allscripts to EPIC
 - Cohort discovery tool (Mining EMR), IRB Software, Genomics Data Commons
- I2B2 vs. TriNetX for cohort discovery

Questions and Discussion

Thank You!