# Mini Summit 4.4 Pilot Efforts to Connect Across Agencies: What's Next to Further Open Data Science

Health Datapalooza 2016

May 10, 2016



#### Session Presenters

#### Louis Fiore, MD, MPH

Clinician, Clinical Investigator, and Healthcare Systems Engineer (VA)

The Department of Veterans Affairs Point of Care Clinical Trial and Precision Oncology Programs:

Using Electronic Medical Record Systems and Health System Data in Support of Learning

Healthcare System Activities

Connie Lee, MPH, FACHE Healthcare Administrator (VA)

Michelle Berny-Lang, PhD Program Director (NCI)

Jennifer Lee, MD, PhD Clinician-Investigator (Stanford and VA)

Lesley Park, PhD, MPH Epidemiologist and BD-STEP Fellow (Stanford)

Big Data Scientist Training Enhancement Program

Peter Kuhn, PhD Physicist (USC)

Jeannine Walston Patient Educator and Advocate (Integrative Cancer Care)

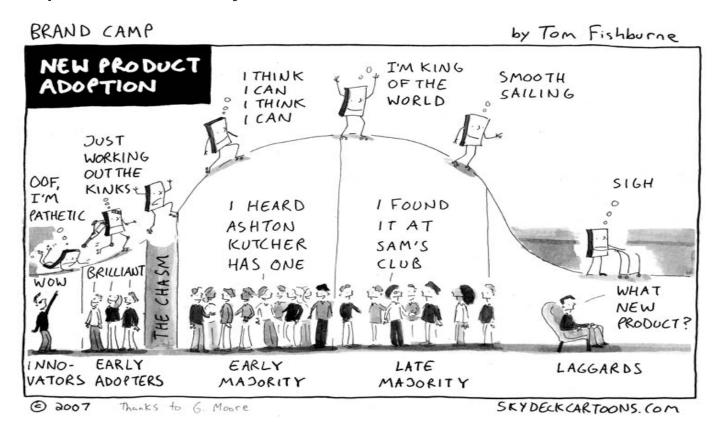
Patient Life Span Navigation



#### National Cancer Moonshot Initiative Research Areas

- Cancer Vaccine Development
- Early Cancer Detection
- Immunotherapy and Combination Therapies
- Genomic Profiling of Tumor and Surrounding Cells
- Enhanced Data Sharing
- Pediatric Cancer
- Oncology Center of Excellence
- Vice President's Exceptional Opportunities in Cancer Research Fund

# Concept... to Reality



#### **Discussion Question Themes**

Collaborations

Training and Education

National Learning Healthcare System

Enabling and Engaging Patients

Data Science Community Contributions

#### Discussion Questions: Collaborations

• How did a collaboration enable your research efforts that might not have been possible otherwise?

• Where do we need better collaborations/connections between data; communities; and people to accelerate cancer research?

# BD-STEP: Collaborations NCI & VA



**SU Physical Scientists VA Clinician-Investigators** 

### **Stanford**

CS/E, Physics, Statistics, PHS, Informatics



#### **VA - Palo Alto**

Cooperative Studies Program HSR&D, Clinical Services



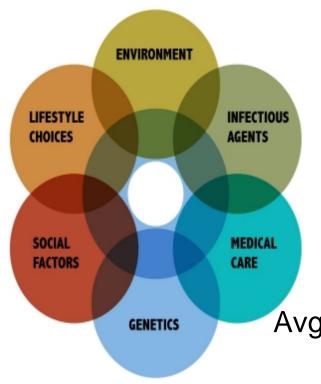
# **EHR-based Data Access & Sharing**

Real-world research mill

8M people in a single year

15-year capture of granular HCS data





HCS: a Zettabyte (10<sup>21</sup>) per year

Whole genome sequencing now costs under \$1000

Avg. life expectancy in Atwater, CA is 87 years but just 8 miles away, it's only 78.

HCS + Individual Daily Living + Community

# Discussion Questions: Training and Education

How do we ensure that our scientific researchers are properly equipped and enabled to utilize the data and computing resources becoming available?

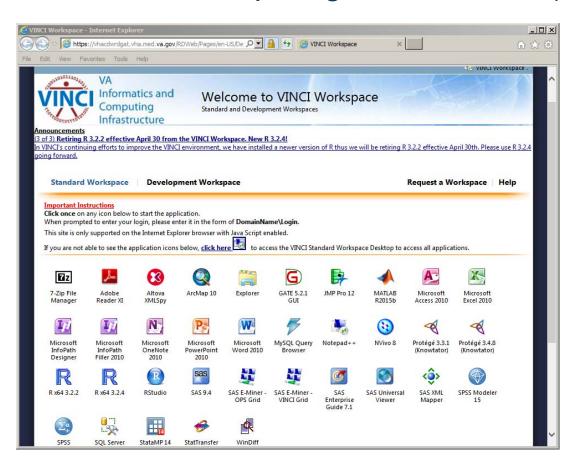
How do we ensure that clinical care teams can understand, utilize, and communicate to the patient complex data and interpretations of the data?

# Stanford/VA Palo Alto Data Bootcamp



**Discussion Question Themes** 

# VA Informatics and Computing Infrastructure (VINCI)



**Discussion Question Themes** 

# Big Data to Clean Data

#### VHA Health Information System **Electronic Medical Administrative** Record Record (centralized) Diagnostic Codes Inpatient/Outpatient Procedure Codes Laboratory Data Utilization Pharmacy Data (centralized) Pathology Mortality Radiology **Progress Notes VACS Database**

#### Patient Survey

Adherence
Alcohol Use
Drug Use
Quality of Life
Health Behaviors
Provider Relationship

#### Substudies

Telephone Interviews
Blood Samples
DNA Samples
Neurocognitive
Psychiatric Testing
Focus Groups

#### **Provider Surveys**

Adherence Comorbidity Health Behaviors Provider Characteristics

**Discussion Question Themes** 

# Discussion Questions: National Learning Healthcare System

How can we use what we are learning in cancer research to accelerate the improvement of the lives of cancer patients and survivors?

• How can the care and outcomes of current cancer patients and survivors inform the research enterprise?

# Discussion Questions: Enabling and Engaging Patients

How can data science enable and empower patient care?

• What are avenues for patients and their families/caregivers to be partners in research and care? How do we ensure engagement?

# Discussion Questions: Data Science Community Contributions

• How do we engage more data scientists to work in biological and clinical sciences? What opportunities exist for the data science community to contribute?

How can we leverage existing data resources to truly demonstrate the societal benefit of cancer research (e.g., the non-financial "return on investment")? How can the data science community inform this assessment?



www.cancer.gov/espanol