### **Breakout Session 1**

## Data Use in the Time of Screening and AI: Defining Consensus, Value, Context and Responsibilities

#### **Quantitative Imaging Workup XVIII:**

Optimizing Thoracic Imaging to Detect and Manage Early Lung Cancer/COPD

November 4-5, 2021 (Virtual)

## Questions

- 1. What do we envision using big data for currently?
- 2. Assuming the infrastructure exists for supporting the data, curating, monitoring and releasing it, what are challenges is using it and putting it together
- 3. Mechanisms to continuously collect data versus single data dump.
- 4. Control on what data is used for and by whom
- 5. Measures of success
- 6. Who should do this

# 1. What do we envision using big data for currently?

- Focus of the database
  - lung cancer screening or
  - all the other possibilities, e.g. cardiac disease, emphysema etc.
- Make it as broad as possible
- Biggest value of lung cancer screening > general health evaluation

- I-ELCAP as an example
  - Earlier papers focused on lung cancer screening-related topics
  - In recent years, starting to shift more towards other secondary findings

# 2. Assuming the infrastructure exists for supporting the data, curating, monitoring and releasing it, what are the challenges in using it and putting it together

#### • Existing resources:

- I-ELCAP
- MIDRC- seek out to institutions that have different populations to get representative groups
- GO2 Foundation- over 800 centers Center of Excellence, around 50 continuum care centers.

#### • Challenges:

- No uniform way to collecting data collection.
- Each group/institution have different policies on how they want to share the data and what restrictions they want to put on the data
- Need of critical information beyond CT images, e.g. clinical information such as medical history, physical & diagnostic workups, lab results, etc.
- How do we reach out to all the screening sites out there?

# 2. Assuming the infrastructure exists for supporting the data, curating, monitoring and releasing it, what are the challenges in using it and putting it together (Continued)

- Population-based approach:
  - SEER-Medicare database
    - Links all fee-for-service data and additional links with research identifiable files: demographics, zipcode, addresses, prescriptions, diagnosis and procedure codes, and lab test results.
  - Link to commercial insurers
  - Allows for much richer longitudinal use
- Potential collaboration with the VA
  - Resources, technology, will and interest are all there
  - Standard health measures already stored within the VA corporate data warehouse
  - Availability of data beyond CT images Million Veteran Program (MVP)

# 3. Mechanisms to continuously collect data versus single data dump

- What is the most important thing to get?
  - Images? Metadata? Annotated images?
- A database that continue to evolve
  - Keeping up with technology
  - Continue to update results (e.g. normal value)
- Challenges with curation on a continuous basis
  - Data cleaning

### 4. Control on what data is used for and by whom

- Who would have access?
  - Patient concerns
  - Institution concerns (may vary on whether industry can have access to it)
  - This can be a driver for start up companies in particular to help them accelerate in a meaningful way
- How could this be done?
  - Through NIH?
  - Outside NIH? Partner up with major organizations?
    - Prevent Cancer, GO2 Foundation
    - HHS-AHRQ
    - National Library of Medicine,
    - CMS ResDAC (U of Minnesota)
- Cost
  - Minor investment: Computer infrastructure
  - Major investment: Coordination (site oversight, contractual arrangements)

#### 5. Measures of success

- To assess how beneficial it is, need to be able to track
  - who uses it,
  - #. of publications,
  - #. of products developed as a result of the use of data

#### 6. Who should do this

- Who would support something like this?
  - Grants? Philanthropic donations?
  - Need to scope out the cost
  - Organizations to seek out:
    - Prevent Cancer foundation
    - GO2 Foundation
    - American Lung Association
    - QIBA