

# Data – For What?

- ❖ Data is accumulating – fast
  - Have the opportunity to harness it or let it pass us by
- ❖ Should solving the cancer informatics challenge be a priority?
  - Opportunity to improve the efficiency of the discovery engine
  - Opportunity to bridge between discovery and health
  - Lessons learned in cancer research can be leveraged by other aspects of cancer care and medical disciplines
  - Risk of losing data assets currently, getting behind
  - Risk of reducing resources assigned to other priorities
    - Takes activation energy (e.g., resources, change in practice)
    - Being an early adopter means that you can invest money in a plan where the outcome is unclear
  - Legitimate concerns about privacy and loss

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### **GOAL = EMBRACE CANCER INFORMATICS**

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# Data – Finding carrots in the soup

## ❖ Data availability and infrastructure

- Democracy of information
- Technical hurdles – resolved and to resolve
- Integration and exchange
- Interoperability
- Governance

## ❖ Sense-making

- Analytics and methods development
- Visualization and data representation
- Wrestling with quality concerns
- Appropriate use of experimental and observational data

# Data – Finding carrots in the soup

## ❖ Data availability and infrastructure

- Democracy of information

**GOAL = EMBRACE SOLUTIONS**

- Governance

## ❖ Sense-making

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# Stakeholders or Partnerships?

- ❖ Patient voices, consumers, advocates - US
- ❖ Cancer centers
- ❖ National research infrastructure/NCI/coop. groups
- ❖ Researchers, quantitative scientists, basic scientists
- ❖ Dell/TGen, Patients/Physicians/Clinical trialists
- ❖ NCCN, sites/outcomes researchers, payors, pharma
- ❖ Community oncology/McKesson, users, patients
- ❖ EHR companies, IT companies
- ❖ Federal agencies and society

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**GOAL = ECOSYSTEM OF PARTNERS**

- ❖ DCC, PCOR, Patients/Physicians/Clinical trials
- ❖ NCCN, sites/outcomes researchers, payors, pharma
- ❖ Community oncology/McKesson, users, patients
- ❖ EHR companies, IT companies
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# Generating trust

- ❖ Patients, people, society, us
- ❖ Privacy and security
- ❖ Accountability
- ❖ Ownership

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- ❖ Patients, people, society, us
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**EMBRACE THE COMPLEXITY**