Overview

1. City of Hope and ORIEN
2. LabKey Adoption
3. Lessons Learned & Future Plans
4. Q&A
City of Hope and ORIEN
City of Hope National Medical Center

- National Cancer Institute
- CAR-T Therapies
- Diabetes
- Precision Medicine and ORIEN
Precision Medicine

Today

Average patient

Standard treatment

Improved Outcome

No benefit

Adverse side effects

2030

Precision medicine

Genome

Environment

You

Population health data

Data analytics

Personalised treatment

Improved Outcome

Improved Outcome

Reduced side effects

*Image from Australian Government: Chief Scientist
ORIEN: Oncological Research Information Exchange Network

- City of Hope is 3rd of 19 other institutions within the network
- Over 100,000 patients consented for clinical and genomic data across the network
- Matches cancer patients to clinical trials
Total Cancer Care Protocol (TCC)
- A Common Protocol for Patient Enrollment

1. **Follow** the patient throughout his/her **lifetime** permitting sharing of data and information

2. Study the patient’s tumor using **molecular technology**

3. Maintain **ongoing contact** with each patient
Total Cancer Care Protocol (TCC)
- A Common Protocol for Patient Enrollment

Collect from enrolled patient:

1. **Follow the patient** throughout his/her lifetime permitting sharing of data and information
2. **Study the patient's tumor** using molecular technology
3. **Maintain ongoing contact** with each patient
Total Cancer Care Protocol (TCC)
- A Common Protocol for Patient Enrollment

Collect from enrolled patient:

Tissue Specimens

1. Follow the patient throughout his/her lifetime permitting sharing of data and information
2. Study the patient's tumor using molecular technology
3. Maintain ongoing contact with each patient
Total Cancer Care Protocol (TCC)
- A Common Protocol for Patient Enrollment

Collect from enrolled patient:

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Molecular Data

1. **Follow the patient** throughout his/her lifetime permitting sharing of data and information
2. **Study the patient’s tumor** using **molecular technology**
3. **Maintain ongoing contact** with each patient
Total Cancer Care Protocol (TCC)
- A Common Protocol for Patient Enrollment

Collect from enrolled patient:

1. **Tissue Specimens**
2. **Molecular Data**
3. **Longitudinal Clinical Data**

**A Common Protocol**

1. **Follow the patient** throughout his/her lifetime permitting sharing of data and information
2. **Study the patient's tumor** using **molecular technology**
3. **Maintain ongoing contact** with each patient
ORIEN Research Operations Workflow

1. Patient Identification
2. Specimen Identification and Shipment
3. Clinical Data Abstraction
4. Tumor and Normal Sequencing
ORIEN Workflows

Research Operations:
- Patient Identification
- Specimen Identification and Shipment
- Clinical Data Abstraction
- Tumor and Normal Sequencing

Staff:
- Clinical Research Coordinators
- Biospecimen Coordinators
- Data Analysts
ORIEN Workflows

Research Operations

- Patient Identification
- Specimen Identification and Shipment
- Clinical Data Abstraction
- Tumor and Normal Sequencing

Clinical Research Coordinators
Biospecimen Coordinators
Data Analysts

Clinical Data
Genomic Data
Platform Fatigue

Patient Identification
Brokering the data
Brokering the data
Brokering the data
Brokering the data

Internal ORIEN Team

3rd Party Vendors (M2Gen)

Researchers

Data Scientists
Brokering the data

Researchers
3rd Party Vendors (M2Gen)
Internal ORIEN Team

PHI? Permissions?
Quality Control? Auditing?
Collaboration?

Data Scientists
Struggle is real

Time vs. Headaches Graph:
- Headaches increase over time.

Image of a person looking at a laptop with their hands on their head.
EHR data available through the EDW

Image from Lightbeam Health Solutions
Specimen Data Elements

- Tumor Specimens (Pathology Reports)
  - Final Diagnosis
  - Gross Description
  - Type of Biopsy
  - Specimen Site of Origin
  - Primary/Metastatic
  - Tumor Content

- Normal Specimens (LIMS)
  - Patient Sample ID
  - Quantity
  - Collection Time
  - Sub Sample Type
Clinical Data Elements

- Demographics
  - Gender, Ethnicity, Race
  - Date of First Contact
  - Date of Diagnosis
  - Primary Site of Diagnosis
  - Histology

- Clinical Staging
  - cT, cN, cM Stage

- Pathological Staging
  - pT, pN, pM Stage
  - Performance Status at Diagnosis
  - Most Recent Performance Status
  - Current Disease Status

- Comorbidities

- Drug-related Toxicities >Grade 2

- Family History of Cancer

- Treatment
  - Surgery/Biopsy History
  - Current Status on a Clinical Trial

- Treatment Medications
  - Immunotherapy
  - Anti-neoplastic
  - Hormone
  - Radiation

- Imaging

- Tumor Markers

- Vital Status
Integrate/Access the EDW for Data
### Query Development (cont.)

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### Dataset: Demographics, All Visits

This section will capture basic patient information for the identified specimens.

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### Specimen Identification and Shipment

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#### Tumor Specimens: Genitalia Mastectomy (A)
- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

#### Tumor Specimens: Genitalia Mastectomy (B)
- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

#### Tumor Specimens: Genitalia Mastectomy (C)
- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

#### Tumor Specimens: Genitalia Mastectomy (D)
- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

#### Tumor Specimens: Genitalia Mastectomy (E)
- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

#### Tumor Specimens: Genitalia Mastectomy (F)
- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

#### Tumor Specimens: Genitalia Mastectomy (G)
- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

#### Tumor Specimens: Genitalia Mastectomy (H)
- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

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- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

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- **Description:** Benign Breast Tissue
- **Observations:**
  - No evidence of malignancy

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- **Description:** Benign Breast Tissue
- **Observations:**
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- **Observations:**
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- **Observations:**
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- **Description:** Benign Breast Tissue
- **Observations:**
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- **Description:** Benign Breast Tissue
- **Observations:**
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- **Observations:**
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- **Observations:**
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- **Observations:**
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#### Tumor Specimens: Genitalia Mastectomy (Z)
- **Description:** Benign Breast Tissue
- **Observations:**
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**References:**
- LabKey Software
- Epic Systems Corporation

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Data Sources

- Labatory Inventory Management Systems (LIMS)
- Electronic Health Records (EHR)
- Pathology Reports
- Clinical Trial Management Systems (CTMS)
- Disease Registries

Enterprise Data Warehouse (EDW)

LabKey Data Curation

- Manual Abstraction
- Extract-Transform-Load (ETL)
- Natural Language Processing (NLP)

LabKey Workflows

- Reports
- Data Repository
- Views
- Tasks

City of Hope
EPIC/Clarity \( \rightarrow \) tgen\( i \) \( \rightarrow \) DNAanexus

Specimen \( \rightarrow \) Sequencing

Workflow Management

EDW

LabKey

Genomic Data

REDCap

Pathology \( \rightarrow \) EDW

LIMS

Meta-data layer

CTMS

i2e

HPCC at COH
Natural Language Processing
Proof of Concept Done but....
MOMENTUM

Development
Development

Proof of Concept

MOMENTUM
Development

Proof of Concept

MOMENTUM
Development

Development

Proof of Concept

Production

MOMENTUM
No Man’s Land

Development

POC: No Man’s Land

Production
Lessons Learned & Future Plans
Lessons Learned

- Solve the data problems first
- Build opportunistically!
- Manage expectations
- Train your users
Future Plans

• User Permissions
  – Sync with IRB Access Systems, CTMS (OnCore) and DNAnexus via API
• Precision Imaging and Data Science
  – Use APIs to connect to LabKey datasets for Data Science
• Running genomic pipelines through LabKey
• Development
  – User Interface
Future Plans (Cont.)

- Laboratory Inventory Management System (LIMS)
- Disease Registries
- Genomics
- Disease Registries
Front Door
ORIEN Team

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Joanne Baclig
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Thanh Luong
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Acknowledgements

Leadership
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Steven T Rosen, MD
Michael A Caligiuri, MD
Sorena Nadaf, MS MMI
Larry Kwak, MD PhD
Samir Courdy, MBA

Development
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Thank you!
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