10 MILLION PATIENTS • 4,100 PHYSICIAN PROVIDERS • 1,240 PRACTICES/CLINICS • 22 HOSPITALS • 67 COUNTIES
BACKGROUND

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Brief History

The Start
2010 - State of Florida Cluster Grant
2011 - Supplement to UF CTSA

Continued Growth
2014 - James and Esther King Biomedical Research Foundation Grant: Tobacco-related CVD and Cancer

Patient-Centered Outcomes Research Network (PCORnet) Clinical Data Research Network Site
2015 - OneFlorida

Multiple Studies in the Network and Expanded Collaborations
More to follow in presentation

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Goal: To Create an Enduring Infrastructure & Capacity for:

- 10 MILLION PATIENTS
- 4,100 PHYSICIAN PROVIDERS
- 1,240 PRACTICES/CLINICS
- 22 HOSPITALS
- 67 COUNTIES

Inclusive of Diverse Populations
What Works Better for Whom Under What Circumstances?
Conducted in Real World Settings to Accelerate Translation to Practice and Adoption
The Science of Fostering the Uptake of Evidence-Based Best Practices Into Diverse Health Care Settings

Learning Health System
Stakeholder Engagement: People, Clinicians, Health Systems, Payers, Industry
Statewide Partners

- University of Florida and UF Health
- Florida State University and the Regional Campus Practice Partners
- University of Miami and UHealth
- Orlando Health
- Florida Hospital
- Tallahassee Memorial HealthCare
- Health Choice Network
- Bond Community Health Center Inc.
- Miami Children’s Health System
- WellFlorida Council
- Capital Health Plan

Note: DUA with Emory To Extend CTSA Collaborations
### Synergies & Programs: Florida CTSA Programs Provide Blended Infrastructure and Expertise

#### Florida CTSA Programs

**UF CTSI Programs**
- Implementation Science
- Biomedical Informatics
- Translational Workforce Development
- Recruitment & Multisite Study Support

**FSU College of Medicine Programs**
- Clinical Research Network
- Pilots

**Miami CTSI Programs**
- Biomedical Informatics
- Community Engagement and Cultural Diversity
- Regulatory Knowledge and Support

#### OneFlorida Clinical Research Consortium Programs

**Integrated Clinical Research Program**
- Community Clinician/Health System Engagement
- Integration, Implementation, Maintenance of Certification

**Patient and Citizen Scientist Program**
- Participant Recruitment

**Data Trust Program**
- Data Query & Analytics
- Honest Brokers

**Patient Population Program**
- Hypertension, Obesity, DMD Rare Disease, Tobacco Cessation, Child Health

### Stakeholder-Engaged Governance, Pragmatic Clinical Trials, Implementation Science, Learning Health Systems

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National Synergies

We are part of a national network of PCORnet Partners, most of whom have CTSAs

- Accelerating Data Value Across a National Community Health Center Network (ADVANCE)
- University of Chicago: Chicago Area Patient-Centered Outcomes Research Network (CAPriCORN)
- Greater Plains Collaborative (GPS)
- Kaiser Permanente & Strategic Partners Patient Outcomes Research To Advance Learning (PORTAL) Network
- Mid-South CDRN
- PaTH: Towards a Learning Health System
- Louisiana CDRN (LACDRN)
- National Pediatric Health Learning System (PEDSnet)
- New York City Clinical Data Research Network (NYC-CDRN)
- Scalable Collaborative Infrastructure for a Learning Healthcare System (SCILHS)
- Patient-oriented SCAlable National Network for Effectiveness Research (pSCANNER)
- Patient-Centered Network of Learning Health Systems (LHSNet)
- OneFlorida Clinical Data Research Network

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THE ONEFLO RIDA DATA TRUST

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Goal - The OneFlorida Data Trust: A Central Data Repository to Facilitate Research

DATA
- Florida Medicaid and Medicare*, Florida Cancer Registry and Florida Vital Statistics with Identifying information
- Limited Data Sets from EHRs from Clinical Partners
- Patient Consent for Registry and/or Study Participation
- PROs and Other Study Data Collection

ACCESS
1. OneFlorida Research Mart
2. Submit Protocol to OneFlorida IRB and Steering Committee
3. Local Honest Brokers for Limited Data Sets IDs and/or Patient Contact Info
4. Data Provided

* Florida Medicare Pending
The Data Trust in August, 2016

- **+1** 4 Years of Completed Data
- **+50M** 139,709,225 Encounters
- **+120M** 248,334,772 Diagnoses
- **+5.6M** 8.2 Million Patients
- **+199M** 317,557,519 Procedures
- **+10.7M** 66.7 Million Medications Dispensed

**Additional Details:**
- 10 Million Patients
- 4,100 Physician Providers
- 1,240 Practices/Clinics
- 22 Hospitals
- 67 Counties
The Data Trust Today

- 10.6 Million Patients
- 331 Million Procedures
- 94 Million Medications Dispensed
- 168,774,799 Encounters
- 330,295,972 Diagnoses
- 4.5 YEARS of Completed Data

Additional statistics:

- +0.5
- +29M
- +82M
- +2.4M
- +14M
- +27M
WE CONTINUE TO BUILD THE DATA TRUST

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Ongoing Activity

Q3 Data
Most technical teams have already submitted data for Q3 2016

Adult Medicaid Data
Final approval from ACHA received
UF Team in process of creating dataset for Data Trust

Florida Cancer Data System

Additional Partners
Bond Clinic
Capital Health Plan EHR data
WellFlorida
How Do I Access the Data?

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Currently For Queries

- **Develop a Query**
  We will talk about this soon!

- **Submit the Query to the Query Coordinator:**
  Florida State University:
  Jessica De Leon jessica.Deleon@med.fsu.edu
We are implementing i2b2 software and loading it with Data Trust data to enable researchers to conduct anonymous queries on their own.
For Cohort Discovery & Data Sets

- Must be approved by the OneFlorida Steering Committee

- The Front Door link to forms will be available soon. In the meantime contact:
  - Florida State University: Jessica De Leon jessica.deleon@med.fsu.edu

- OneFlorida IRB approval is required before any data is released
The Making of a Query
Understand the Data Elements

- High level data elements
- Data Dictionary available
Case Study: Hypertension

What type of hypertension?
- Resistant Hypertension
- Essential Hypertension

What information to use?
- ICD codes
- Systolic and diastolic values
- Inpatient or outpatient or both

Resistant Hypertension Example:

The RHTN computable phenotype was created by constructing a drug exposure variable that took into consideration the number of antihypertensive medications an individual was prescribed at any point in time over the course of the OneFlorida dataset. RHTN was defined as any blood pressure requiring four or more antihypertensive drugs, or uncontrolled blood pressure (>=140/90) on three antihypertensive drugs. RHTN cases had to meet the definition criteria twice during the data period, at least 30 days apart.

Caitrin Rowe & Rhonda Dehoff; University of Florida College of Pharmacy
Case Study: Obesity

Child cohort:
- Age < 20 years at vital measure
- Two, same day height and weight measures in the cohort time window
- Weight measurements >1lb and <661lb
- Height measurements >8in and <118in
- BMI measurements >2 and <80
- Vital measurement dates that occur after birth date

Adult cohort:
- Age ≥ 20 years
- At least one height measure ≥ 20 years of age and two weight measures in the cohort time window
- Weight measurements >50lb and <700lb
- Height measurements >48in and <84in
- BMI measurements >15 and <90
- Vital measurement dates that occur after birth date
OneFlorida Studies

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CTSI-Affiliated Investigators & Funded Projects Leveraging OneFlorida

Health Systems Demonstration Project
- Predictive Algorithms
- Social Determinants of Health
- Pediatric Safety

Heart Health
- OPTI-BP
- ADAPTABLE
- NHLBI-INVESTED

Pediatrics
- U18 Pediatric Quality Measurement Program
- Center of Excellence

Cancer Prevention
- NCI-funded HPV Vaccine
- 6As Tobacco Pediatrics
- Childhood Cancer Survivors

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CTSI-Affiliated Investigators & Developing Projects Leveraging OneFlorida

- **Precision Medicine**
  - NIH: SEEC: Developing Application with Emory-Morehouse CTSA Collaboration

- **Heart Health**
  - NHLBI K12
  - CVD Risk Reduction: Using Big Data & Implementation Science
  - DOD – Ischemia-IMT

- **Pediatrics: Comparative Effectiveness Research**
  - PCORI: Antibiotic Use and the Microbiome

- **Cancer Prevention**
  - NCI: Social Media and Colorectal Cancer Screening
  - JEk: Expansion of Data Trust to Include Genetic & Tumor Information
  - NCI & Others: Hep C Screening

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