COHORT DISCOVERY

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Integrated Data Repository (IDR)
Clinical and Translational Science Institute (CTSI)

Integrated Data Repository (IDR)

- A large-scale clinical data warehouse

- UFHealth data

  - ~1.9 million patients, >1.5 billion facts

- Enables new research discoveries

  as well as improvements in the quality
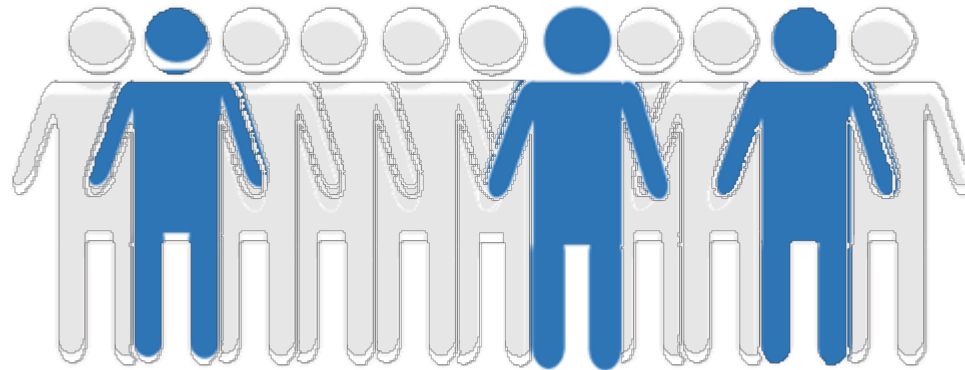
  and safety of patient care

Services offered by IDR

1. Cohort discovery

2. Retrospective patients' data

3. Consent2Share

1. Cohort discovery

- Feasibility of study

i2b2

- Data exploration and cohort discovery tool

- Query curated data

- Returns an obfuscated number of unique patients that meet query criteria

i2b2 example

i2b2 instances available at UF

ACT
The ACT Network
Powered by NCATS CTSA Program

125 MILLION PATIENTS

41 SITES CONNECTED

AND GROWING.

Connected to ACT:
Boston University
Children's National
Columbia University
Duke University
Emory Univ./Morehouse Univ.
Harvard University
Indiana University
Johns Hopkins University
Mayo Clinic
Medical College of Wisconsin
Medical University of South Carolina
New York University
Northwestern University
Ohio State University
Oregon Health & Science University
Pennsylvania State University
Stanford University
University of Alabama at Birmingham
U. of Arkansas for Medical Sciences
University of California, Davis

University of California, Irvine
University of California, Los Angeles
University of California, San Diego
University of California, San Francisco
Univ of Cincinnati/Cincinnati Children's
Univ of Colo/Children's Hosp. Colorado
University of Florida
University of Illinois-Chicago
University of Kansas
University of Kentucky
University of Minnesota
University of North Carolina at Chapel Hill
University of Pittsburgh
University of Southern California
UTHealth Houston
UT Health San Antonio
UT Southwestern
Vanderbilt University Medical Center
Virginia Commonwealth Univ.
Washington University in St. Louis
Weill Cornell Medicine

Staging for ACT:
Case Western University
Dartmouth College
Scripps Research / Scripps Health
Tufts University
University at Buffalo
University of Massachusetts
University of Miami
University of Michigan
University of New Mexico
University of Rochester
University of Texas Medical Branch
University of Utah
University of Virginia
University of Washington
University of Wisconsin-Madison
Wake Forest University

OneFlorida
Clinical Research Consortium

- Florida Hospital (AdventHealth)
- Orlando Health
- Tallahassee Memorial Inpatient
- Tallahassee Memorial Outpatient
- UF Health
- University of Miami
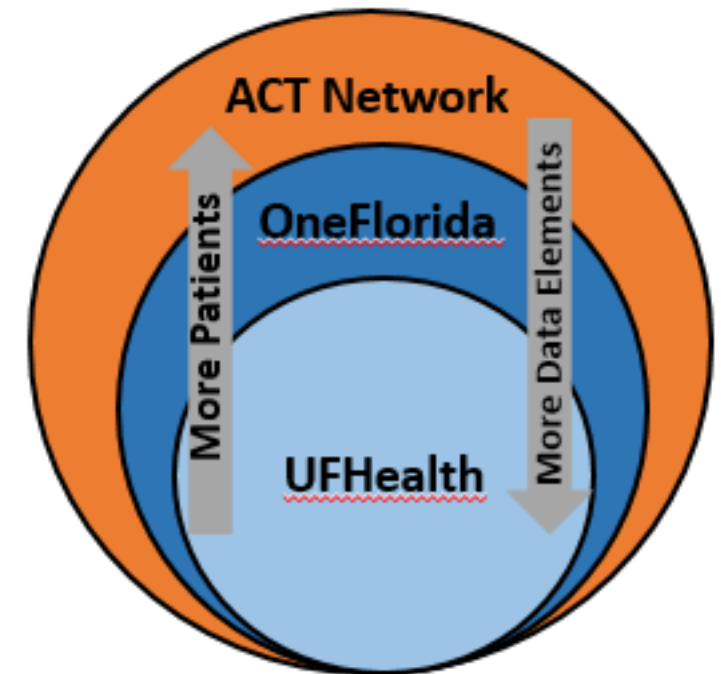- Nicklaus Children's Hospital
- Capital Health Plan
- Florida Medicaid

UFHealth
UNIVERSITY OF FLORIDA HEALTH

- Gainesville
- Jacksonville

i2b2 instance	Geography
UFHealth	Gainesville, Jacksonville
OneFlorida	Florida
ACT Network	Nationwide

i2b2 instances available at UF

i2b2 instance	Patients	Facts	Geography
UFHealth – GNV	1.24M	1.21B	Gainesville
UFHealth – JAX	0.75 M	0.35B	Jacksonville
OneFlorida	13.6M	18.3B	Florida
ACT Network	125M	>50B	Nationwide

Data as of September 1, 2019.

i2b2 resources

UFHealth i2b2
- Project overview: https://idr.ufhealth.org/i2b2/
- Training: http://i2b2.idr.ufhealth.org/education/, https://idr.ufhealth.org/i2b2/i2b2-training-tools/
- Request access: https://idr.ufhealth.org/i2b2/i2b2-registration/
- i2b2 support: i2b2support@ahc.ufl.edu

OneFlorida i2b2
- Project overview: https://onefloridaconsortium.org/front-door/onfli2b2/
- Training: https://onefloridaconsortium.org/front-door/onfli2b2/, go to "Training" section
- Request access: https://onefloridaconsortium.org/i2b2/webform/i2b2.html
- i2b2 support: i2b2support@onefloridaconsortium.org

NCATS ACT i2b2
- Project overview: http://www.actnetwork.us/FloridaCTSI
- Training: http://www.actnetwork.us/FloridaCTSI, click on "How-To Resources"
- Request access: https://idr.ufhealth.org/services/act-i2b2-cohort-discovery/ncats-act-i2b2-registration/
- i2b2 support: ACT-I2B2Support@ahc.ufl.edu

2. Retrospective patients' data

- Reliable

- Secure

- Patients privacy protected

Access Patients Data

UF Health	OneFlorida	ACT Network
• Need an approved IRB • Submit an online data request form https://idr.ufhealth.org/services/analyst-data-support-services/idr-data-request-form/ • Contact IDR Data Team IRBDataRequest@ahc.ufl.edu	• Need an approved IRB for OneFlorida • Contact OneFlorida Front Door Team OneFloridaOperations@health.ufl.edu	• Need an approved IRB at each participating institution • Need to find a collaborator at an institution of interest • Submit an online data request form https://idr.ufhealth.org/services/analyst-data-support-services/idr-data-request-form/ to get UF data • Contact IDR Data Team IRBDataRequest@ahc.ufl.edu

3. Consent2Share (C2S)

- Recruit patients to participate in a study

- Patients agreed to be contacted for a future study

  - Provide contact information for patients that fit inclusion criteria for the study

- 64,230 patients with signed C2S by Sept. 1, 2019

  - <18 years of age: 9,825

  - >= 18 years of age: 54,405

Future

THANK YOU