

COHORT DISCOVERY

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Integrated Data Repository (IDR)
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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

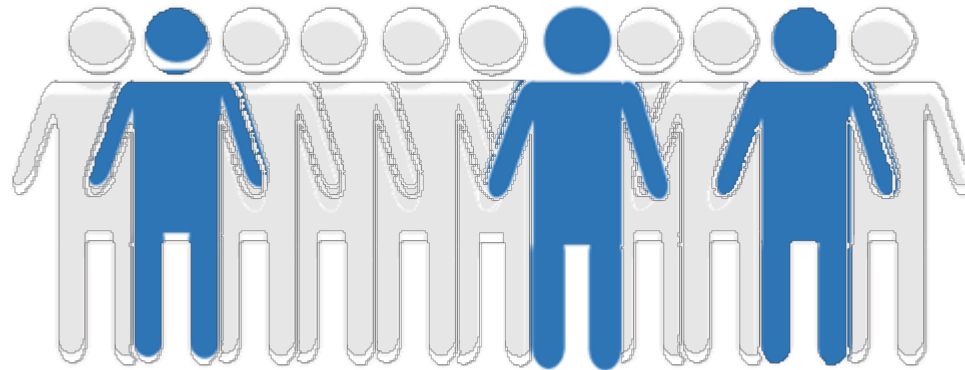


Services offered by IDR

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

The screenshot displays the i2b2 Query & Analysis Tool interface. The browser address bar shows `i2b2.idr.ufhealth.org`. The page header includes the tool name, project information (Cohort JAX, 03/2013-06/2019), user name (Tanja Magoc), and navigation links (Find Patients, Analysis Tools, Message Log, Help, Logout).

The interface is divided into several sections:

- Navigate Terms:** A sidebar menu with categories like Assessment Scales, Demographics, Diagnoses, Findings, Immunizations, Lab Results, Medications, Personalized Medicine, Procedures, and Visit Details.
- Workplace:** A workspace area containing the user name 'tmagoc'.
- Previous Queries:** A list of recent queries, including 'diabets_A1c7_child [9-4-2019] [tmagoc]'.
- Query Tool:** The main query editor. The query name is 'diabets_A1c7_child'. The temporal constraint is 'Selected groups occur in the same financial encounter'. The query is structured into three groups:
 - Group 1:** E08-E13 Diabetes mellitus [52066 patients] and 250 Diabetes mellitus [41077 patients].
 - Group 2:** Hemoglobin A1c/Hemoglobin.total in Blood (LOINC: 4548-4) [72420 patients] > 7 %.
 - Group 3:** Child (< 18 years old) at visit.The groups are connected by 'AND' operators. Each group has a green box indicating 'one or more of these'.
- Run Query:** A button to execute the query, with a 'Clear' button and a 'New Group' button.
- Show Query Status:** A section showing the results of the query. It displays the number of patients as 41 ± 3 for the query 'diabets_A1c7_child'.

i2b2 instances available at UF



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



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

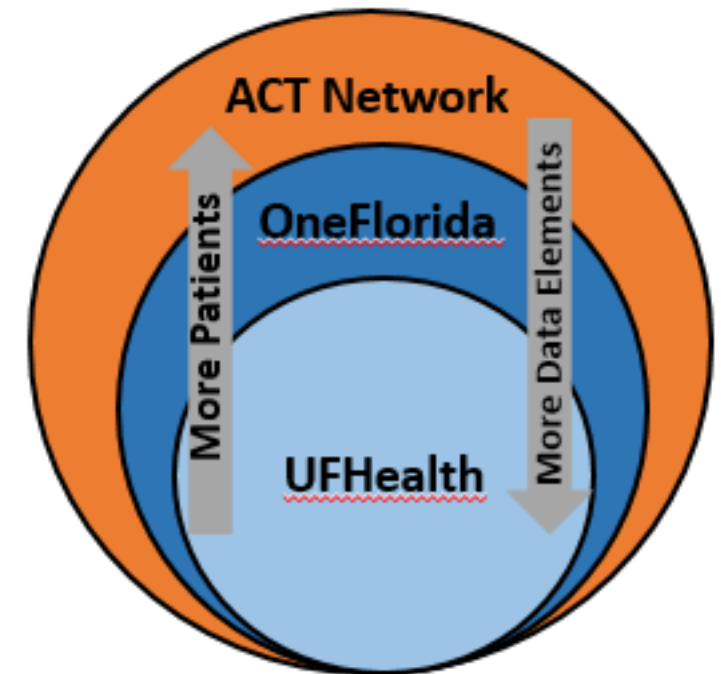


i2b2 instance	Geography
<u>UFHealth</u>	Gainesville, Jacksonville
<u>OneFlorida</u>	Florida
ACT Network	Nationwide

i2b2 instances available at UF

i2b2 instance	Patients	Facts	Geography
<u>UFHealth</u> – GNV	1.24M	1.21B	Gainesville
<u>UFHealth</u> – JAX	0.75 M	0.35B	Jacksonville
<u>OneFlorida</u>	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



patientID	date	diag_code	diag_icd_type	diag_desc
P1	12/7/2005	784	ICD9	HEADACHE
P3	11/12/2012	V14.7	ICD9	No-vaccine allergy
P1	11/28/2012	305.1	ICD9	Tobacco use disorder
P2	4/12/2011	V76.51	ICD9	COLON CA SCREENING
P6	5/7/2014	345.9	ICD9	Epilep NOS w/o intr epilep
P17	3/19/2004	401.9	ICD9	HYPERTENSION NOS
P9	12/14/2006	434.9	ICD9	CEREB ART OCCL S INFARCT
P2	7/25/2008	599	ICD9	URINARY TRACT INF NOS
P3	5/15/2008	401.1	ICD9	BENIGN HYPERTENSION
P45	7/8/2013	V58.63	ICD9	Lng use antiplate/thrombotic
P1	11/4/2006	V76.12	ICD9	SCRFFN MAMMOGRAPHY NFC

PatientID	hospital	encounter_date	sex	race	ethnicity
P1	UFHP CLINIC	9/11/2018	MALE	WHITE	HISPANIC
P5	UFHP CLINIC	9/11/2018	FEMALE	WHITE	NOT HISPANIC
P17	UFHP CLINIC	9/13/2018	FEMALE	BLACK	NOT HISPANIC
P3	UF	9/13/2018	MALE	WHITE	NOT HISPANIC
P4	UFHP CLINIC	9/13/2018	FEMALE	WHITE	HISPANIC
P6	UFHP CLINIC	9/18/2018	MALE	ASIAN	NOT HISPANIC
P23	UF	9/19/2018	FEMALE	BLACK	NOT HISPANIC
P2	UFHP CLINIC	9/19/2018	FEMALE	WHITE	NOT HISPANIC
P6	UFHP CLINIC	9/19/2018	MALE	ASIAN	NOT HISPANIC

PatientID	lab_result	lab_unit	normal_low	normal_high	lab date	lab_name
P1	0.02	x10E3/uL	0.03	0.46	9/19/2018 10:22	EOSINOPHILS ABSOLUTE COUNT
P1	11	ng/mL			9/19/2018 10:22	DELTA-9-THC-CARBOXYLIC ACID URINE CONFIRMATION
P2	3.3	mmol/L	3.3	5.1	9/19/2018 10:22	POTASSIUM
P3	None Detected				9/19/2018 10:22	BENZODIAZEPINE SCREEN, URINE
P4	0.5	%	0	2	9/19/2018 10:22	BASOS
P17	0.61	x10E3/uL	0.2	0.7	9/19/2018 10:22	MONOCYTES ABSOLUTE COUNT
P23	10	IU/L	0	35	9/19/2018 10:22	ALT (SGPT)
P3	11	mmol/L	8	16	9/19/2018 10:22	ANION GAP
P12	3.07	x10E6/uL	4	5.2	9/19/2018 10:22	RED BLOOD COUNT
P1	34	seconds	25	38	9/19/2018 10:22	PARTIAL THROMBOPLASTIN TIME

Access Patients Data



- 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
 - \geq 18 years of age: 54,405



Future



THANK YOU