COHORT DISCOVERY

Dr. Tanja Magoc
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

- 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
i2b2 instances available at UF

<table>
<thead>
<tr>
<th>i2b2 instance</th>
<th>Patients</th>
<th>Facts</th>
<th>Geography</th>
</tr>
</thead>
<tbody>
<tr>
<td>UFHealth – GNV</td>
<td>1.24M</td>
<td>1.21B</td>
<td>Gainesville</td>
</tr>
<tr>
<td>UFHealth – JAX</td>
<td>0.75 M</td>
<td>0.35B</td>
<td>Jacksonville</td>
</tr>
<tr>
<td>OneFlorida</td>
<td>13.6M</td>
<td>18.3B</td>
<td>Florida</td>
</tr>
<tr>
<td>ACT Network</td>
<td>125M</td>
<td>&gt;50B</td>
<td>Nationwide</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Need an approved IRB</th>
<th>Need an approved IRB for OneFlorida</th>
<th>Need an approved IRB at each participating institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Submit an online data request form <a href="https://idr.ufhealth.org/services/analyst-data-support-services/idr-data-request-form/">https://idr.ufhealth.org/services/analyst-data-support-services/idr-data-request-form/</a></td>
<td>Contact OneFlorida Front Door Team <a href="mailto:OneFloridaOperations@health.ufl.edu">OneFloridaOperations@health.ufl.edu</a></td>
<td>Need to find a collaborator at an institution of interest</td>
</tr>
<tr>
<td>Contact IDR Data Team <a href="mailto:IRBDataRequest@ahc.ufl.edu">IRBDataRequest@ahc.ufl.edu</a></td>
<td></td>
<td>Submit an online data request form <a href="https://idr.ufhealth.org/services/analyst-data-support-services/idr-data-request-form/">https://idr.ufhealth.org/services/analyst-data-support-services/idr-data-request-form/</a> to get UF data</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contact IDR Data Team <a href="mailto:IRBDataRequest@ahc.ufl.edu">IRBDataRequest@ahc.ufl.edu</a></td>
</tr>
</tbody>
</table>
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

NEED HELP?

WE CAN HELP

IRBDataRequest@ahc.ufl.edu
THANK YOU