CFRI

Children’s Foundation Research Institute

- An institution formed as a partnership among:
  - Le Bonheur Children’s Hospital
  - University of Tennessee Health Science Center
  - Children’s Foundation of Memphis

- CFRI manages
  - Laboratory research
  - Clinical trials management
  - Clinical research projects
  - Biomedical informatics support
  - BioStatistics support

- CFRI’s purpose is to support faculty research
BMIC
Bio-Medical Informatics Core

- Support clinical and transformational research
- Research data management (REDCap)
- Research design and statistical support
- PRD
- Research honest brokerage
- Grant application development
The PRD Team

- Tee Viangteeravat, Ph.D.
- Naga Nagisetty, MS
- Grady Wade, Ph.D.
- Eunice Huang, M.D.
The Problem

- Researchers want access to data
- Researchers have to get IRB approval to get access to the data they want
- Often researchers need aggregate information before they can get the IRB; usually to support getting the IRB
- Researchers often need aggregate information for grant applications
- And it all revolves around Protected Health Information (PHI)
Our Solution

- A de-identified database with query capabilities
- PHI is hidden
- Results are only shown in aggregate
- Visual display oriented
- User friendly
- Unlimited number of queries
PRD

Pediatric Research Database

- Tool for supporting researchers
  - finding study cohorts
  - building research hypotheses
- Allows researchers to search data that is de-identified before they obtain IRB approval
- Designed with academic researcher in mind
- Empowers researcher to be somewhat independent in data querying
Research workflow

Key Players
- PI
- Statistician
- Informaticist

Manuscript preparation, submission, and revision

IRBs

Result Discussion

Statistician Analysis

Dataset Generation

Feasibility Assessment

Project Inception

PRD

10/14/13  Hruby GW, et al. J Am Med Inform Assoc 2013;0:1-5. doi:10.1136
PRD Contents

- Encounter level and patient level data
- Derived from administrative and EMR databases
- All Le Bonheur Inpatient, Observation, Ambulatory Surgery, ER and Urgent Care encounters 2009 - 2012
- Demographic data
- All diagnoses and procedures in ICD-9 codes as abstracted for billing purposes (admission, principal, and secondary)
- All Patient Refined Disease Related Grouping (APR-DRG) grouping assignment for all encounters
- Body Mass Index (BMI) categories for Inpatient and Observation encounters (~50% of encounters)
- Imaging data
**Some Basic Numbers**

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<th>Patients</th>
<th>Encounters</th>
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<tr>
<td>AS</td>
<td>13.2%</td>
<td>7.2%</td>
</tr>
<tr>
<td>ER</td>
<td>78.3%</td>
<td>75.8%</td>
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</table>
Some Questions to Explore

For NICU patients who died what was the top principal diagnosis?

Is there geographic pattern for children with diabetes that were admitted as inpatient with ketoacidosis?

Number of asthma patients receiving x-ray?

Identify high risk population of asthma patients who also have a bronchitis episode?
Live Demonstration
Things We Are Working On

Points we are working on:

- Ability to create pdf’s from the dashboards
- Additional data elements
- Additional functionality
Informatics Workflow for PRD

EMR/EHR

PHIS

EXTRACT

non-HL7, spreadsheet, csv, tab separated value, etc.

PHIS

EXTRACT

ASCII text via Blue Button

virtual private network

Virtual Private Network

PRD STAGING

Data Harmonization Checking & Cleaning
(UTHSC Firewall)

Virtual Private Network

PRD PRODUCTION

Transform & Load + de-identified Data

Cohort discovery Hypothesis generation
(UTHSC Firewall)

Institutional Review Board (IRB) Approval

REDCap

REDCap web-based

EDC Survey Data via computer mobile technologies

Natural language + Machine learning =

(tokenizing
syntax parsing
lexical mapping rules
semantic analysis)

(Targeting NSF or NLM funding sources)
Thank you!
Questions?

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