**Emory+Children’s Pediatric Research Retreat**

**Informatics Roundtable Discussion**

**1/27/12**

Intro by Ann Mertens, PhD, Director of COPRH

* The Research Informatics Core is managed within the Center for Clinical Outcomes and Public Health (CORPH)
* The Research Informatics team will work closely with Children’s IS&T to manage EPIC and other information systems report requests
* The model is that there is a defined amount of help and expertise provided during the discovery period of projects, but ongoing effort will be paid for informatics expertise once grant funding is secured

Prabhu Shankar, MD, MS, Research Informatician

* Has prior clinical experience in many health areas but has chosen informatics as a field of focus
* Prior experience at CHOP and Cedars Sinai working with EPIC
* Will work with Tal Senior, RN, and Children’s IS&T to help fulfill research data needs

**Areas of discussion**

1. Data modeling
	1. Need a de-identified way to help with this
	2. Need to know if collection methods are relevant to get biologically relevant results
	3. Any disconnect between researchers and informatics folks with regards to capturing clinically relevant and usable data needs to be addressed
	4. Working out data sharing and data use agreements between investigators and institutions needs to be addressed
	5. Access to clinical data to correlate with other research data like genotypic data needs to be addressed
	6. Need to figure out how to capture data in a discrete, usable fashion – this is one of Prabhu’s main area of interest
2. Assessing how many patients fit particular exclusion/inclusion criteria for a given clinical trial and other clinical research study
	1. Tal Senior (Children’s IS&T) has done this before for people
		1. First – Identify discrete variables
		2. Second – Developer can extract from EPIC
	2. De-identified data can be requested to identify research cohorts; once project receives IRB approval, data with identifiers can requested
	3. Need to establish patient and disease registries to identify cohorts for research purposes
	4. Need to address issue of who ‘own’s patient’s data and gives permission for use if covers more than one Divisions. Currently CHOA IRB has some requirements in place, but does not cover IRB requests through Emory IRB.
3. Data Sharing
	1. Building domain general systems to allow collected data to be used for multiple purposes
	2. Process would be facilitated by universal consent for CHOA patients (see below)
4. Universal consent
	1. i2b2 (Informatics for Integrating Biology and the Bedside) can be used to consent patients when they enter the hospital system
	2. Tal Senior indicated there are talks to incorporate i2b2 into the data warehouse plan
	3. Jim Nettles indicated that Vanderbilt has a universal consent form and they have a very high consent rate (>90%)
5. Handling data in databases that preceded EPIC
	1. Should these databases be maintained or is there an opportunity to incorporate them with EPIC?
	2. This is a service the Informatics Core is looking to offer in the future – if all the data collected and stored in those local databases can somehow be captured discretely in Epic, is it possible to retire those databases. The data from Epic can then be pulled into planned data warehouse automatically. From data ware house, we can then populate any patient/disease registries.. If there are specific reasons/needs to keep the local databases, then possibilities to incorporate those databases into data warehouse will be looked into. This is in line with the CHOA initiative to have a central data warehouse.
	3. EPIC is used first and foremost for patient care, so even though data collection/manipulation/analysis is a recognized need, EPIC can be and need to be configured to capture data discretely andthen, as mentioned in 5b, can pull data out from Epic and load into central data warehouse/ local registries for secondary uses like outcomes analyses and research.
6. Transition of care issues – CHOA and Emory Hospital use different electronic medical records
	1. Discussion ongoing between Dept of Informatics at Emory and IS&T at Children’s
	2. May require a few test cases to see what can be done
7. Educational Opportunities
	1. Will plan a CORPH Seminar including IS&T and the Research Informatics Core to address:
		1. How does EPIC work?
		2. What is reasonable to expect for research purposes?
		3. What data is already there that might provide value for research purposes?
	2. Will also provide other more detailed instructional/informational sessions for those who are interested in digging in the details
	3. Can also schedule time with Prabhu to discuss your own project needs and what is feasible
8. Approach for investigators to take
	1. Investigator should generate a list of core/common data variables they think they would like to collect and track
	2. Schedule a meeting with Prabhu to discuss and determine what is feasible and what will work best
	3. The future vision is once a query is build, an investigator can run the same query at any time to get updated results based on new data available

**Important dates and links:**

1. **Emory+Children’s Pediatric Research Pilot Application information and application:**

<http://www.pedsresearch.org/news/article/2012-center-pilot-rfa>

***Applications due March 1, 2012***

1. **SPH thesis form** for offering your project available to an MPH or MSPH student in the Department of Epidemiology:

<http://www.sph.emory.edu/cms/departments_centers/epi/thesis_form.html>

1. **How to Make an Informatics Core Request:**

Follow the path below to access current Intake form (You need to login to Careforce Connection to access it).

Careforce  Frequently Used Tools  Quick Access to Patient Care Forms  Clinical Report Request

OR

Copy and paste the below URL in a new tab after logging into Careforce:

<http://apps/forms/Lists/Clinical%20Report%20Request/Item/newifs.aspx?List=efcc3043%2D7424%2D476f%2Da2db%2D5ecc05fa60b3&Web=3c815ed7%2Dd843%2D42f4%2D9517%2D44b09a332b20>

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UPDATE: A recent talk by Robert Grundmeier, Clinical Informatician from CHOP, highlighted the issues related to using retrospective data from Epic for research purposes and stressed the need for configuring the systems (Epic) to get clean and discrete data for outcomes and research. Prabhu Shankar can provide additional details on his visit.