AGENDA
Date 4/14/16

Attendees:
Chris Stoeckert
Heather Williams
Frank Manion
Mathias Brochhausen
David Birtwell
Helena
Marcy Harris

Not today:
Jihad Obeid - on vacation somewhere warm
Asiyah
Oliver
Jie

Notes:
Review of previous action items:
- Reach out to research coord/PIs who run biobanking ops for broad consent
  ○ Ask about process of consenting or volunteer for specimen :)
  ○ Chris interviewed JoEllen Weaver at UPenn
    ■ Chris attached PDF of the concept map done in CMAP to meeting announcement
    ■ Also filed under "Visualizations" in Google Document folder.
      https://drive.google.com/open?id=0B81h9ah4tAM_LW95aEoyYnpPc1E
- Frank and Jihad to communicate about next meeting logistics.
  ○ We didn't communicate and it's too late now...
- Frank: get technical group going.
  ○ First meeting is scheduled for April 21, 2016.
  ○ US/Canada Dial-in: 1-888-450-5996, Participant passcode: 981720
  ○ Url: https://connect.umms.med.umich.edu/manionmtg/
  ○ Group members are Chris, Mathias, Frank, Oliver, and Asiyah

Mapping of additional sites regarding processes for informed consent.
- We need to add rights and obligations on both the investigator and research subject side
- Everyone is encouraged to use the paradigm used by Chris in the concept map of the UPenn biobank.
- Please use CMAP for these
- Chris will add some additional details.
- Mathias proposed that we use the Github site for collaboration on these discussions as the grant specifically called out this would be used as a collaboration platform. He volunteered to coordinate a common place for these discussions that would be visible to the reviewers of the grant.

New members/introductions - Drs. Sung Choi and Jody Platt

- ● Group did not object to new membership
- ● Drs. Choi and Platt will probably join us next time

Review of mailing list membership
- ● The group doesn't even remember that there is a mailing list
- ● Frank will dig back through his notes and see where our mailing list actually is and who is on it!

Review of ICO
- ● Links to material:
  - ○ Review ontology in ontobee: http://www.ontobee.org/ontology/ICO
  - ○ WebProtege: http://webprotege.stanford.edu/#Edit:projectId=2dc11696-19bf-4412-b59d-17d205dd25fe
  - ○ Working Spreadsheet: https://docs.google.com/spreadsheets/d/1ATxYVq0KlRgsv6oFq278ZPUyu6Rw_6tbxoz3RIpSpmc/edit?usp=sharing
  - ○ We spent a little time looking at the spreadsheet Frank has started. Once we get a handle on what is actually in ICO we will need to discuss how to reconcile with the legal and authorization frameworks. Some of this will be discussed on the upcoming technical call.

Action items:
- ● Frank to add Drs. Sung Choi and Jody Platt to the mailing list
- ● Mathias will set up github site under the ICO github repository after contacting Asiyah
- ● Frank to make sure Jihad adds Jody and Sung to the Calendar invite
- ● Everyone to continue collecting use cases and processes associated with consent

=======================OLD NOTES================

AGENDA
Date 3/31/16

Attendees:
Chris Stoeckert
Heather Williams
Jihad Obeid
Frank Manion
Mathias Brochhausen
Asiyah
Jie

Not today:
David Birtwell
Helena

Notes:
- Ontology meeting: http://ncorwiki.buffalo.edu/index.php/Clinical_Terminology_Shock_and_Awe
  - Chris may organize a Cancer Ontology session
  - CI4CC: Cancer Informatics meetings: may include ontology work (http://www.ci4cc.org)
- Review of minutes from last meeting
- Frank to start tech Ontology Group
- Meeting moved to 2pm.
  - Jihad may have conflicts next two meetings. Will send alternate options.
- Decided to go with the one use case (#1 below)
  - Look at 3: U Penn, U Mich, and Duke broad biobank consent (need to add complete Mich consent)
  - Find common elements between those 3
  - Define Broad Consent:
    - Prospective collection of specimens for unspecified future research
    - Could be included with another consent form for specific research
    - Or could be not associated with specific research
  - How is the consent obtained then how is the information captured. (Focus on the consenting process used). Process:
    - May vary between institutions
    - Collect process steps information (what are the steps)
      - Starting point: Researcher has an idea: for clinical research (not broad consent)
      - Researcher writes protocol
      - Protocol submitted to IRB (if research requires a consent form then consent form submitted with IRB protocol)
      - Protocol and consent approved by IRB (may involve request for changes to protocol and consent)
      - Consent form is IRB stamped with approval date and expiration date (1 year)
      - It requires annual approval
      - Research begins: patients are recruited (IRB approved methods)
        - Advertising
        - If you have permission to contact patients directly, then you can do that.
        - Recruit through PI's clinic
        - May have other for broad consent for biobank
      - Prescreen to identify who needs to be consented (based on prelim eligibility criteria)
      - Broad consent eligibility criteria (everyone seen at the institution: inpat or outpat)
      - In some cases it may be driven by a specific research project (e.g. melanoma) in which it may have eligibility criteria.
      - … (consenting)...finish later
  - Then figure out what the gaps are in ICO for use case #1
- Next meeting:

- ○ Look at 3: U Penn, U Mich, and Duke broad biobank consent (need to add complete Mich consent)
- ○ Find common elements between those 3
- ○ Need to continue the process
- ● ACTIONS:
  - ○ Reach out to research coord/PIs who run biobanking ops for broad consent
    - ■ Ask about process of consenting or volunteer for specimen :)
  - ○ Frank and Jihad to communicate about next meeting logistics.
  - ○ Frank: get technical group going.

=======================OLD NOTES================

AGENDA
Date 3/17/16

Attendees:
Chris Stoeckert
Heather Williams
Jihad Obeid
Frank Manion
David Birtwell
Helena
Jie

Not today:

Notes:
- ● Review of minutes from last meeting
- ● During the last meeting we came up with an outline to proceed (see below)
  - ○ Use cases (see below)
  - ○ Review gaps in ICO using webprotege based on the used cases (one by one)
  - ○ Ontology is developed off-line then brought back to this group for review
  - ○ See links to Ontobee & webprotege below
- ● Ontology team (the team should be the technical team)
  - ○ Frank Manion: organizer
  - ○ Chris, Frank, Mathias, Oliver He, Asiyah
  - ○ Task will be to take the terms we have been given and fit into ICO and OBO Foundry (BFO and RO).
  - ○ Tools:
    - ■ Review ontology in ontobee: http://www.ontobee.org/ontology/ICO
    - ■ WebProtege: http://webprotege.stanford.edu/#Edit:projectId=2dc11696-19bf-4412-b59d-17d205dd25fe
    - ■ WebProtege allows for increased sharing and for commenting on terms and relationships.
- ● Subject expertise contribution will occur during these meetings.
- ● Going over first use case:

○ Need to understand how different organizations are handling it.
● Next meeting dates?
　　○ Who cannot make the 4pm time slot?
　　　　■ Marcy
　　○ ACTION: Jihad to ask if most folks prefer 4pm or 2pm.
● Agenda for next meeting:
　　○ Decided to go with the one use case (#1 below)
　　　　■ Look at 3: U Penn, U Mich, and Duke broad biobank consent (need to add complete Mich consent)
　　　　■ Find common elements between those 3
　　　　■ How is the consent obtained then how is the information captured. (Focus on the consenting process used).
　　　　■ Then figure out what the gaps are in ICO for use case #1
　　○ Then we can spin off the technical group to dive into ICO design
========================OLD NOTES=================

AGENDA
Date 3/3/16

Attendees:
Chris Stoeckert
Heather Williams
Jihad Obeid
Mathias Brochhausen
Helena Ellis
Jie Zheng
David Birtwell
Frank Manion
He Y.

Not today:

Notes:
● Agenda based on last meeting notes:
　　○ identify use cases to model: take one or two from the grant. Grant has four use cases:
　　　　■ 1) Identify cases and controls from a population of patients that have EDTA blood or DNA specimen available *who have consented to be recontacted for future research study request (broad biobank consent)*
　　　　　　● *Duke's language "Future Contact: Duke Researchers who are studying your materials may want to contact you if they need more information that is important for their research. Researchers will only be allowed to contact you if their study is approved by the Duke Institutional Review Board and if you indicate 'yes' below."*
　　　　■ 2) "Identify large or small, normal tissue, intestine samples –from the Pathology paraffin archives, from patients with Parkinson's disease who **have consented to a Broad Consent protocol** (e.g.,

one from Duke that allows access to retrospective as well as prospective excess tissue).”

- ■ 3) “and who **do** have a plasma sample in the Biorepository that **has been consented for allowable use of specimens.”**
- ■ 4) “***Identify specimens available for research use for researchers engaged in a patient centered outcomes research network”***

- ○ Review gaps in ICO using webprotege (e.g. what we said in the grant)
- ○ do the types support the competency questions
- ○ Discussed Process of development:
  - ■ Ontology developers draft ontology model
  - ■ Then Bring back to this call to make sure we captured the domain and there is agreement with the model.
    - ● Jie posted ICO paper link: http://ceur-ws.org/Vol-1327/icbo2014_paper_54.pdf
- ○ ACTION: FRANK: would like to take use cases, go through to see what is modeled in ICO supports use cases. So:
  - ■ REVIEW all 4 use cases and define them clearly as we did in #1.
  - ■ NEXT MEETING:
    - ● define 2nd use case.
    - ● identify Frank's ontology team.
- ● NOT DISCUSSED ON 3/3 (tabled)
  - ○ Terms relevant to biobanking that require def: https://github.com/ICO-ontology/ICO/issues
  - ○ Inclusion of d-acts terms in ICO.
  - ○ What are the core terms defined in ICO and how related to d-acts
  - ○ Can use biobank consent from our repository as an example to test the core terms in the ICO. In addition, general informed consent terms needed by biobank will be added in the ICO and biobank specific consent terms will be added in OBIB
  - ○ Track in github.
  - ○ Can review ontology in ontobee (http://www.ontobee.org/ontology/ICO vs. protege.):
    - ■ jie updated ICO on webProtege:
    - ■ http://webprotege.stanford.edu/#Edit:projectId=2dc11696-19bf-4412-b59d-17d205dd25fe
- ● Housekeeping:
  - ○ switching to webex. TBA
  - ○ meeting frequency: keep at 2 weeks but skip next one.
  - ○ next meeting: 3/31