Hi, everyone.

Thanks for a great meeting yesterday. I really appreciate your time and commitment to this project, and am looking forward to getting a good demonstration and JBI paper out in the first quarter of next year.

Here are some highlights from our meeting:

1.)  Prajwal Vijendra (Duke Data Science student) has skills and time to commit to this project in the next few months. I will meet with him (and pull in Eric Monson and Jay Pedersen) for advice as I need) to get Prajwal up to speed on the GraphDB.  For now, I will focus on generating queries that can demonstrate the value of SNOMED semantic relationships – and give us some short term data for the Journal of Biomedical Informatics (JBI) paper I need to finish submit for and us.  For step 1, we will focus on the Neo4J queries for now at least, and not worry just yet about visualization tool. (Although Eric has found that Gephi could be an option if we wish.)

2.) Tom Balmat from Duke Research Computing has ideas, including R Shiny app that might get us something to start with for the publication and just advancing our understanding of the data and good questions we might explore. I will include Tom in my discussions with Prajwal to get us toward a tangible demonstration of something.

3.) Sigfried Gold (PhD candidate at U of Maryland and long-time terminology / data viz enthusiast) has some interesting ideas for looking at this data. I will give him access to data and other project documents to get him familiar with what we have done so far and what our goals are. If anyone can point him to GitHub stuff on the SNOMED queries, please do.  Meanwhile, he send me these links to follow-up on the longitudinal analysis topic that came up during the call yesterday:

[https://hcil.umd.edu/eventflow/](https://urldefense.proofpoint.com/v2/url?u=https-3A__hcil.umd.edu_eventflow_&d=DwMFaQ&c=imBPVzF25OnBgGmVOlcsiEgHoG1i6YHLR0Sj_gZ4adc&r=CZe7kTe8fUi3mxoPBysLWZ2LXh27wu66zcBAF1zL2c4&m=oC08DXtwezt7QBudCatLr-ElqLou3NOBDps4aZwI1Xw&s=_fCDZYFE4vsWUh4hIJbPb9jk_28YoUWBOZOOKuvbVXc&e=)

[https://www.cs.umd.edu/hcil/lifeflow/](https://urldefense.proofpoint.com/v2/url?u=https-3A__www.cs.umd.edu_hcil_lifeflow_&d=DwMFaQ&c=imBPVzF25OnBgGmVOlcsiEgHoG1i6YHLR0Sj_gZ4adc&r=CZe7kTe8fUi3mxoPBysLWZ2LXh27wu66zcBAF1zL2c4&m=oC08DXtwezt7QBudCatLr-ElqLou3NOBDps4aZwI1Xw&s=a9yWy_NQgKBHjW6oKoe2aYquI7VKZabAm9w0mm35aTs&e=)

4.) Jay is interested in exploring all of these ideas and strategy for the visualization/analytics approaches. One product Jay can work toward is documenting a process for us to add/update Urea Cycle Disorder (UCD) data into the graph database.  That would be terrific to enable us to add an additional year of data from the UCD study, and set us up to update this work as we need.  (For anyone that is interested, these sites describe the UCD research consortium and the longitudinal study that this data came from: <https://www.rarediseasesnetwork.org/cms/ucdc/About-Us>  and  <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4178008/>  )

5.) Bob and Rima, as always, will drive us with important questions and guide us to outputs that are meaningful for UCD investigators (… and that also will support translational research in other rare diseases.)  Bob will put together an updated scope of work, budget and timeline and send around.  Rima will think of other questions and provide us details as we need, as there are needs to explore the SNOMED and RxNorm data from this study.  Meanwhile, on the call yesterday, we all decided to focus on his problem 1 below to get this started:

**Project 1:**  The goal of this project is to identify who among UCDC enrollees has received a psychiatric diagnosis (list of diagnoses to be provided). The PI wants to focus on specific psychiatric diagnoses.  However, I think that it is also useful to identify persons with suspicions of psychiatric problems that have not been assigned a clear diagnosis as long as the two categories can be defined and separated. This will require identifying persons based on SNOMED (conditions) and RXNORM (treatments) to distinguish those with selected psychiatric diagnoses; Identifying their treatments; and Those with findings indicative of a psychiatric condition with and without accompanying treatments.

6.) In the spirit of continued discussion on this, I will schedule another meeting for January.  Please join if you are interested and let me know if you would like me to try for another time.  Hopefully, I will have better luck with Webex and recording next year so I can offer that to anyone who has to miss the call.  If you want me to take you off my communications for this project, please let me know.

I am looking forward to working together over the next few months for a successful demonstration and JBI paper.

Thank you all for your time and contributions to this project.  It is in innovative and useful and I am sure we can find a strategy and product to share this spring.

Have a wonderful and relaxing holiday!

Sincerely,  
Rachel

-----Original Appointment-----  
**From:** Rachel Richesson, Ph.D.   
**Sent:** Friday, December 6, 2019 3:51 PM  
**To:** Rachel Richesson, Ph.D.; Robert McCarter; Izem, Rima ([rizem@childrensnational.org](mailto:rizem@childrensnational.org)); Campbell, Walter S ([wcampbel@unmc.edu](mailto:wcampbel@unmc.edu)); Jay G Pedersen ([jay.pedersen@unmc.edu](mailto:jay.pedersen@unmc.edu)); Eric Monson, Ph.D.; Prajwal Vijendra; Sigfried Gold  
**Cc:** Tom Balmat  
**Subject:** SNOMED / Neo4J / Data Viz project - Strategy meeting (changed to Wed)  
**When:** Wednesday, December 11, 2019 10:00 AM-11:00 AM (UTC-05:00) Eastern Time (US & Canada).  
**Where:** webex (updated)

WEB-EX Info:

Wednesday, Dec 11, 2019 10:00 am | 1 hour | (UTC-05:00) Eastern Time (US & Canada)

Meeting number: 738 654 419

Password: Wednesday

<https://dukemed.webex.com/dukemed/j.php?MTID=mb4f4ef524a640a16d08d2a1aa90b3377>

Join by video system

Dial [738654419@dukemed.webex.com](mailto:738654419@dukemed.webex.com)

You can also dial 173.243.2.68 and enter your meeting number.

Join by phone

1-650-479-3207 Call-in toll number (US/Canada)

Access code: 738 654 419

I apologize for the confusion and time switch. I will trying for this meeting tomorrow (Wed)  instead of Thursday, so that Bob can join.  Please respond if you can make this meeting. ….  (so far Bob and Signfried and me; hopefully Prajwal; and others…. Fingers crossed.)  
  
For those that cannot make this, I might consider having a Wed meeting and a Thursday one (to give summary of 1st call to those that could not attend, and get feedback)….  And I can certainly record the Wed one tomorrow.

Please accept the invite if you can attend.  I will make a plan from there…

Thanks,

Rachel

Webex TBA.

Inviting Sigfried Gold, informatics and data viz expert and Prajwal Viejendra, Duke MIDS data scientist, for new insights.

Goal is to get a strategy to build demo in 2-3 month time period.