Notes:

PHIN Virtual Conference Presentation
• David would be willing to put together a few slides to present
• Schedule a GoToWebinar and submit that recording

iDASH
• Presenters:
  o Patricia Freeland: Patricia Freeland is a Research and Administrative Assistant at the UCSD School of Medicine’s Division of Biomedical Informatics. She graduated from Tulane University with a Bachelor of Arts in History and Political Science. Her past research experience includes studying infants with hip dysplasia at St. Christopher's Hospital for Children and conducting research on the mental health of children immigrating to the United States with Dr. Marta Tienda at Princeton University. Patricia plans to pursue a PhD in Public Health focusing on Child and Maternal Health.
  o Mike Conway: Since March 2011, Mike Conway has been a postdoctoral researcher at the University of California, San Diego, Division of Biomedical Informatics, working primarily on clinical and public health oriented NLP in Dr. Wendy Chapman’s BLU Lab. Before coming to UCSD, he held postdoctoral positions at Mayo Clinic and the University of Pittsburgh, and was between 2007 and 2009 a Japanese Society for the Promotion of Science postdoctoral fellow in Dr. Nigel Collier’s lab at the National Institute of Informatics in Japan. In 2007, Dr. Conway earned a PhD from the University of Sheffield, Department of Computer Science under the supervision of Dr. Rob Gaizauskas.
• Two repositories: 1 for PHI data and 1 for non-PHI data
• Steps:
  o Step 1: Access, Sign, and Submit your Data Use Agreement (between data owner and iDASH)
    ▪ DUA: http://www.idash.ucsd.edu/procedures
    ▪ DUA that data owner would need to sign and send to UCSD team for the UCSD legal department to sign
    ▪ Any DUA's required by data owners’ organizations, would need to be handled outside of iDASH
      • Have data users sign DUA with data owners
      • Data owners will provide iDASH team a list of people who have signed
      • iDASH team will then provide access to those that have signed data owner’s DUA
Some people also have to get IRB approval

Step 2: Set up an account in the iDASH repository and join a community

- PHI data
  - After DUA is approved an iDASH repository administrator will automatically set up a UCSD Automatic Directory (AD) Account for you.
  - This account information will allow you to access the iDASH repository VPN and will be the first level of authentication.
  - 1-time download of Cisco AnyConnect clier (to connect to UCSD’s VPN)
  - Connect to: vpn.ucsd.edu or vpn-2.ucsd.edu and enter username and password assigned by the iDASH repository administrator
  - Log onto https://idash-data-priv.ucsd.edu/

- Non-PHI data Log-in
  - 1st time: Log-in at https://idash-data.ucsd.edu using the username and password assigned by the iDASH repository administrator
  - Invitation e-mail to join community from Midas
  - Join the community by clicking ‘Join the community’ button

Value?
- Curated environment
- DUAs and access managed by UCSD DBMI
- Ability to store PHI data
- Community of collaborators – e-mailing to different people and getting different responses

Questions: ctri-support@ucsd.edu

Discussion
- Data Use Agreements
  - Usually about 1-day turn-around once DUA has been returned to iDASH
  - International Universities can be challenging, but even this is often done in 3 days
  - Would be active until end of project 2015. If there are extensions, may also extend DUA

- Access to community information: can decide to make certain information public and other information private
- Would it be appropriate to use iDASH as a routing forum?
  - Forum for asking questions/exchanging ideas
  - Would keep processes more consistent for if/when solution developers decided to collaborate on solution.

- Example of use:
  - Multi-institution project – each university has their data in a private folder
  - They use iDASH to share aggregated data within the community

- Funded through 2015
- Could you host iDASH virtually?
  - If data from one state cannot leave that state, could you virtually host in the state in question
- NC DETECT Use Case
  - Using an approved DUA is much easier
  - Will likely handle the DUA process themselves and e-mail the data

Where will the data come from?
Combination of real data, real data highly truncated, or simulation
- Will need a data set sufficient to answer the question, with enough protection that can release the data
- DUA between public health and hospitals may be prohibitive in sharing any data
  - Obligation to hospitals providing data if completely de-identify and randomize
  - May opens up additional IRB issues
- Not going to be a one-size fits all

- Could we organize data sharing issues into categories and create a continuum (easiest situation to more difficult)?
  - Could then proceed with easiest
  - Work to find solutions for more difficult situations
  - For example In San Diego, depending on hospital 2-3 pathways of varying levels of difficulty
  - Proposed levels:
    - **Level 1** – LHD/SHD has flexibility to provide real data without DUA using iDASH (or some similar group).
    - **Level 2** – LHD/SHD has limitations to the data provided without a DUA. Limitations might include no Med IDs, hospitals identified or truncated zip codes.
    - **Level 3** – LHD/SHD needs a DUA to provide any data.
    - **Level 4** – LHD/SHD cannot under any circumstances provide real data.

**Next steps:**

- Follow-up with potential presenters for PHI Virtual Conference – Schedule test (Howard will do Q&A)
- Continue to discuss how iDASH can be utilized to achieve the committee’s goals