H3Africa Consortium Meeting in Accra, Ghana, May 16-18, 2013

Data Sharing, Access and Release Working Group Agenda

Thursday, May 16, 2013, 1:30-3:30 PM

Working Group Chairs: Nicky Mulder, University of Cape Town, R.S.A.

Bamidele Tayo, Loyola University Chicago, U.S.A.

Discussion Facilitators: Audrey Duncanson, Wellcome Trust, U.K.

Maria Giovanni, NIH/NIAID, U.S.A.

Scribe: Julia Puzak, NIH/NIAID, U.S.A.

Agenda

1) Agreement on terms of reference of working group
    a. Develop an H3Africa policy for data release
    b. Develop an H3Africa policy for data access
    c. Provide the H3ABioNet with information about the bioinformatics needs of the H3A Consortium for example, tools for data management, cleaning, analysis, formatting and other bioinformatics strategies for handling genetic/genomic data
2) Review of data sharing model
3) Discussion on data sharing model
    a. Genomic data (Bin #1)
        i. Data types generated and shared
        ii. Data file formats to be archived and stored at project site, H3ABioNet and EGA
        iii. Guidelines needed for defining quality control and validation of each data type
        iv. Guidelines needed for the delineation of responsibilities
    b. Phenotypic data (Bin #2)
        i. *Input from Phenotype Harmonization WG required*
        ii. Data standards and data file formats developed Phenotype Harmonization WG
        iii. Agreement on which phenotypes to be captured and shared
        iv. Guidelines needed for archiving and storing
        v. Guidelines needed for sharing, access and release of phenotypic data
    c. Role of H3ABioNet (Bin #3)
        i. Data file formats for archiving, storage and display
        ii. Usable data file formats
        iii. Tools needed for analysis and visualization
        iv. H3ABioNet creation of a mirrored database
        v. Guidelines needed for who can access data while staged at H3ABioNet
    d. Timelines

i. Timeline needed for processing raw data to quality controlled and validated data set and transfer of data set to H3ABioNet
ii. Timeline needed to transfer phenotypic data to H3ABioNet
iii. Timeline needed for how long data will be held at H3ABioNet before submitting to EGA
iv. Timeline needed for publication embargo

e. Ethics and informed consent (Bin #4)
    i. *Input from Ethics and Regulatory Issues WG required*
    ii. Guidelines needed for reviewing informed consent documents for data storage, access and release
    iii. Who reviews informed consent documents and ensures that they are in line with data, access and release guidelines?
f. EGA data access and release (Bin #6)
    i. What level of access will be granted to data requestors/users via EGA?
    ii. How will data be transferred/obtained by data requestors/users external versus internal?
    iii. Who will be on the data access committee?
    iv. Guidelines needed for data access committee

4) Recommendations to the H3A Consortium
    a. Slides to be included
    b. Questions to be asked and discussed