DATA ACCESS COMMITTEE REPORTING TOOL

Office of Data Science and Emerging Technology – National Institute of Allergy and Infectious Diseases Dr. Christopher S Marcum – Staff Scientist





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Background

- The database of Genotypes and Phenotypes (dbGaP) is a popular database hosting genomic data from institutes across the NIH
- Fach institute has a Data Access Committee (DAC) which grants approval to data access requests (DAR)



1 NEI Age-Related Eve Disease Study (AREDS)

Accession phs000001.v3.p1 Study Disease/Focus Cataract Study Design

Study Markerset Illumina100K, Affymetrix 100K, HumanOmni2.5-4v1 D

Study Molecular Data Type Not Provided

Study Content 16 phenotype datasets, 635 variables, 48 documents, 3 analyses, 3 molecular datasets, 4757 subjects, 6962 samples, 1 sub-studies

Ancestry (computed) Population graph European (575), African American (11), Hispanic1 (2), South Asian (2), Other (3)

NIH Institute EDO --- Eye disease research only, GRU --- General research purposes Study Consent

Release Date 2012-04-05 Embargo Release Date 2016-02-11

Related Terms CRYGS cataract (disease); CTRCT20; Cataract, Membranous; Cataracts, Membranous Cataract; Membranous Cataracts.

The Age-Related Eye Disease Study (AREDS) was initially designed as a long-term multi-center, prospective study of the clinical course of age-related macular degeneration (AMD) and age-related cataract. In addition to ... collecting natural history data, AREDS included a clinical trial of high-dose vitamin and mineral supplements for AMD and a clinical trial of high.

FileSelector Images PubMed PMC MeSH BioProject BioSample

2 Framingham Cohort

Accession phs000007.v31.p12 Study Disease/Focus Cardiovascular Diseases Study Design Prospective Longitudinal Cohort Study Markerset WGS markerset grc36

Study Molecular Data Type Not Provided

Study Content 445 phenotype datasets, 62942 variables, 1342 documents, 3029 analyses, 28 molecular datasets, 15149 subjects, 51778 samples, 8 sub-studies NIH Institute

Study Consent HMB-IRB-MDS --- Health/medical/biomedical (irb, mds), HMB-IRB-NPU-MDS --- Health/medical/biomedical (irb, npu, mds)

Release Date 2020-03-30

FileSelector RunSelector MeSH BioProject BioSample SRA

Embargo Release Date 2020-03-30

Related Terms Body System, Cardiovascular; Cardiovascular; Cardiovascular Body System; Cardiovascular Organ System; Cardiovascular System;

Cardiovascular Systems .

Startup of Framingham Heart Study. Cardiovascular disease (CVD) is the leading cause of death and serious illness in the United States. In 1948, the Framingham Heart Study (FHS) -- under ... the direction of the National Heart Institute (now known as the National Heart, Lung, and Blood Institute, NHLBI) -- embarked on a novel and

3 The Cancer Genome Atlas (TCGA)

phs000178.v11.p8



Current workflow

- Meta information about DARs are available as a table on a webpage
- They can help DACs understand research needs
- But it's difficult to draw insights from just looking at this table

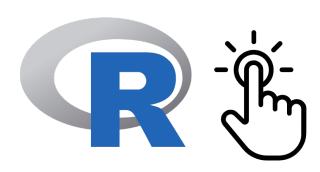
DARs Approved by SO between 05/16/2020 and 11/16/2020 for DAC 'NIAID'

PI	Project	DAR	Study accesion	Submitted by PI	Approved by SO	Approved by DAC	Rejected by DAC	Revision requested by DAC	Data downloaded
1280	849	54528.v6	phs001187.v1.p1	08/28/2020 11:46	09/01/2020 15:00	09/17/2020 18:36			yes in previous version
		73383.v3	phs001201.v2.p1	08/28/2020 11:46	09/01/2020 15:00	09/17/2020 18:43			yes in previous version
		84894.v2	phs001833.v1.p1	08/28/2020 11:46	09/01/2020 15:00	09/17/2020 18:43			yes in previous version
3224	26531	95587.v2	phs000261.v1.p1	09/03/2020 17:34	09/04/2020 12:56	09/15/2020 17:43			no
		95588.v2	phs000247.v5.p3	09/03/2020 17:34	09/04/2020 12:56	09/15/2020 17:43			no
		95591.v2	phs000256.v4.p3	09/03/2020 17:34	09/04/2020 12:56	09/15/2020 17:43			no
3243	1819	82668.v2	phs001079.v2.p1	06/30/2020 06:05	07/01/2020 05:41	08/05/2020 11:21			no
3315	1889	17360.v12	phs000261.v1.p1	07/22/2020 16:25	07/22/2020 18:09	08/19/2020 07:21			no
		17361.v12	phs000247.v5.p3	07/22/2020 16:25	07/22/2020 18:09	08/19/2020 07:21			no
		38638.v10	phs000256.v4.p3	07/22/2020 16:25	07/22/2020 18:09	08/19/2020 07:21			no
3545	3387	46576.v5	phs000641.v1.p1	05/21/2020 10:26	05/26/2020 10:29	07/15/2020 12:39			no
		46605.v5	phs000809.v1.p1	05/21/2020 10:26	05/26/2020 10:29	07/15/2020 12:39			no
		46607.v5	phs000848.v1.p1	05/21/2020 10:26	05/26/2020 10:29	07/15/2020 12:39			no



My Project

 A one-stop-shop R package that can automagically generate a data use report for any DAC using information scraped from the webpage









Report

CDAC Data Access Committee dbGaP Activity Report 2019-11-24-2020-12-14

Hoyin Chu, Christopher Steven Marcum

14 December, 2020

The CDAC Data Access Committee (DAC) currently manages 375 data access requests (DARs) for access to 341 projects in dbGaP.

1 Data Access Requests

Between 2019-11-24 and 2020-12-14 CDAC reviewed 223 DARs. Of these, 212 were accepted, 11 were downloaded, 57 had a previous version downloaded, and 4 were rejected. The average amount of time from when the Principle Investigator (PI) submited a DAR to the final decision by the DAC was 13.6 days. The average time to an accepted decision was 13.6 days, while the average time to a rejected decision was 10.2 days. Figure 1.1 is a barplot comparing the CDAC DAC to time to final decision to the average across all NIH DACs during the same time interval.

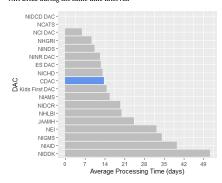


Figure 1.1: Comparison of DAR Processing Time among all DACs



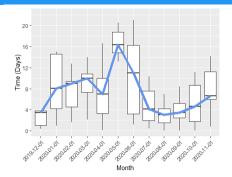


Figure 1.4: DAR Processing Time: From SO Approval to DAC Approval

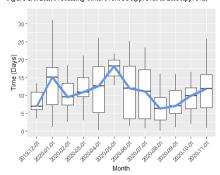
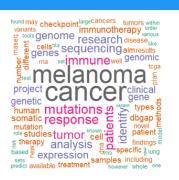
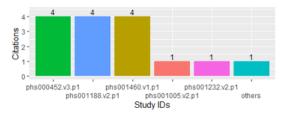


Figure 1.5: DAR Processing Time: From PI Submission to DAC Approval



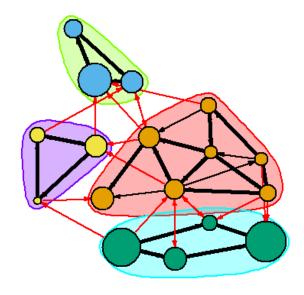






Future Work

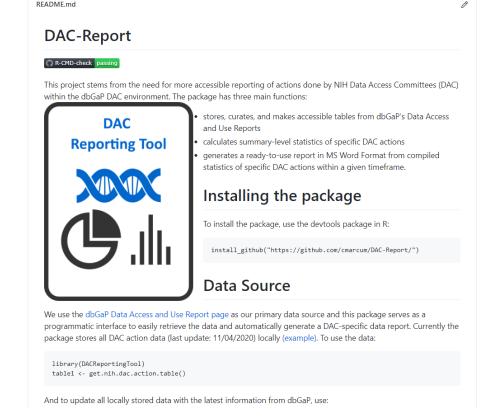
- These data can help us answer more complicated research questions
- Examples: Study-to-Study Network
- What are some unexpected communities?
- How do these networks evolve over time?





A Starting Point

- Open-source practices (version control, continuous integration, documentation...) were followed during the development of the package
- Package will be available to the public and features can be added via pull requests





Thank you!

- ODSET (Office of Data Science and Emerging Technology) Team
- Emerging Leaders in Data Science Fellows
- Everyone who made the fellowship possible



References

- Icons: thenounproject
- Network Image: https://kateto.net/network-visualization

