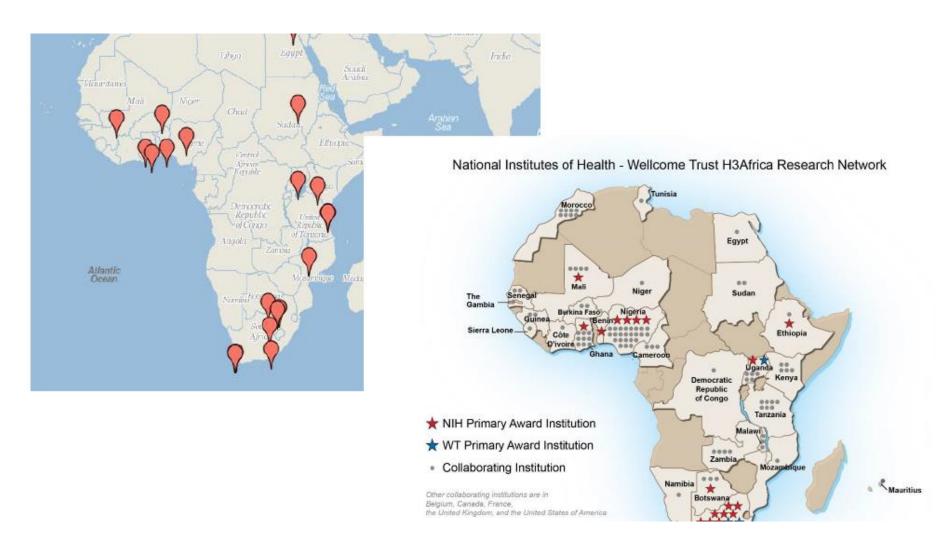


# H3Africa Archive and EGA submission















# Background



- The NIH and Wellcome Trust have funded multiple projects on genomic research
- Data is required to be deposited in public domain
   selected EGA
- European Genome-phenome Archive: https://www.ebi.ac.uk/ega/ is repository for sequence and genotype data
- Data access is controlled by access committees







#### EGA -









#### Wellcome Trust Case Control Consortium









# What is EGA controlled access data anyway?



- Usually human, personally identifiable (Genetic, phenotypic)
- Affiliated to medical research or consortium projects
- Access determined by formal application procedure
- Requires secure storage and distribution
- Informed consents specifying controlled release requirements

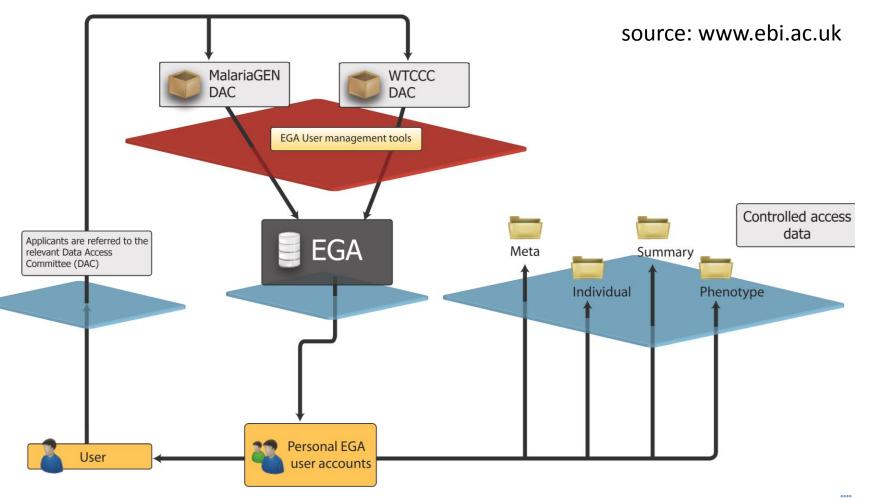


H3ARIONA



## **EGA** Distribution model









# Using Your EGA Account



#### The European Genome-phenome Archive



- EGA Home
- :: Submit to EGA
- :: Information
- :: Help

EMBL-EBI

Contact Us

#### **EXPLORE THE EGA**

- Browse studies
- Browse datasets
- Browse data access committees
- Browse data providers

#### jeffalmeidaking@googlemail .com

- My account
- = Log out

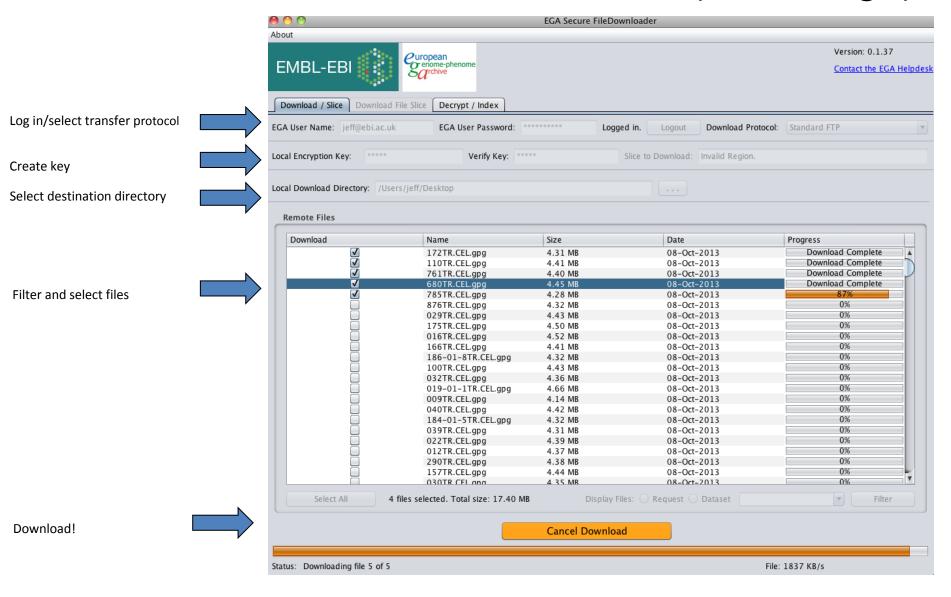
EGA >						
EGA Status						
User: jeffalmeidaking@goog	glemail.com					
Date	Action	Dataset	Packet	Status	Status History	
Date 2013-03-15 10:18:21	<b>Action</b> download	Dataset EGAD00010000280	Packet Raw data File (e.g. CEL/IDAT)	Status 7-10 days until data access	Status History  View status history	
					,	

Research Training Industry

About us

- Download accounts require manual set-ups
- Distribution requires data preparation
- Download accounts expire in 14 days
- Data must be decrypted using keys supplied offline

## Secure EGA Downloader (Pilot stage)





### H3A Archive submission timeline



#### 23 months

Research site -Data generation 2 months Research site- QC genomic & phenotypic data 9 months H3ABioNet-Genomic & phenotypic data stored 12 months
EGA- Genomic &
phenotypic data
available through
DBAC with
publication embargo

Long term
EGA- Genomic & phenotypic
data available through DBAC
without publication embargo



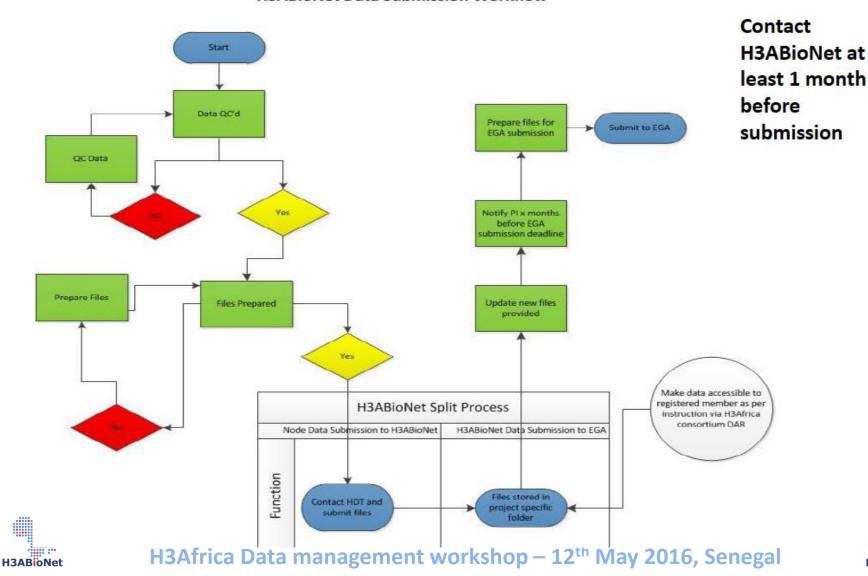








#### **H3ABioNet Data Submission Workflow**











#3	H3Africa Data Archive Projects Submissions Funders Help ayton ▼
	1. Pre-register  2. Receive Submission pack  3. Upload  4. Confirm validation
	Pre-register a submission
	Your name:
	Ayton Meintjes
	Project:
	AWIGEN
	Data types:
	Human whole genome sequence data
	Human exome sequence data
•	,
	Metagenomics sequence data
	Pathogen sequence data
	Estimated date of submission:
	2016/06/01 test submission
	test submission
	Save







### H3A Archive





H3Africa Data Archive

Projects

**Funders** 

Help

Register

Log in

#### **Projects**

TGEN - TrypanoGEN: An integrated approach to the identification of genetic determinants of susceptibility to trypanosomiasis

KDRN - H3Africa Kidney Disease Research Network

AWIGEN - Genomic and Environmental Risk Factors for Cardiometabolic Disease in Africans

RHDGen - The RHDGen Network: Genetics of rheumatic heart disease and molecular epidemiology of Streptococcus pyogenes pharyngitis

T2DSSA - Burden, spectrum and etiology of type 2 diabetes in sub-Saharan Africa

RAFAGENE - RAFAgene: Contribution of genetic variation to pharmacokinetic variability and toxicity in

patients undergoing multi-drug tuberculosis treatment in Sub-Saharan Africa

GSSAX - Identification of genes important for schizophrenia based on genomic analysis of the South African Xhosa population

ACCME - African Collaborative Center for Microbiome and Genomics Research

CAfGEN - Collaborative African Genomics Network

NMRDAC - The Nasopharyngeal Microbiome and Respiratory Disease in African Children

HMGWA - Host and Microbial Genetic Determinants of febrile illness in West Africa

SIREN - Stroke Investigative Research & Educational Network

SBMTb - Systems Biology for Molecular Analysis of Tuberculosis in Ethiopia

CGSHND - Clinical and Genetic Studies of Hereditary Neurological Disorders in Mali







## H3A Archive





H3Africa Data Archive

**Projects** 

Submissions

Funders

Help

ayton -

#### **AWI-GEN**

Genomic and Environmental Risk Factors for Cardiometabolic Disease in Africans

Owner

Michele Ramsay

Submitters

Ayton Meintjes

Submissions

Date started Submitter Status

May 11, 2016, 7:10 p.m. ayton.meintjes New







## H3A Archive



- Don't register directly at EGA
- Pre-register your submissions at least 6 weeks in advance







# **Policy documents**



# H3Africa Consortium Data Sharing, Access and Release (DSAR) Policy

- Related documents (appendices):
  - Data Quality Control and Validation Guidelines
  - H3ABioNet Data Submission Guidelines
  - EGA Submission Guidelines
  - Data and Biospecimen Access Committee Guidelines
  - Data Access Request Form (Form for researchers to request access to data)
  - Data Access Agreement (Form for researchers who have access to data)
  - Policy Statement & Institutional Certification (Form for PIs to submit to EGA)







# **DSAR Policy**



- Outlines the data sharing and access policy of the consortium
- The "principles aim to strike an appropriate balance in ensuring that adequate safeguards are in place to protect participants, while maximizing the ability of investigators to advance research"







## **Principles of DSAR**



- Maximizing the availability of research data, in a timely and responsible manner.
- Protecting the rights and privacy of human subjects who participated in research studies.
- Recognizing the scientific contribution of researchers who generated the data.
- Considering the nature and ethics of the research proposed in establishing the timely release of data, and mechanisms of data sharing.
- Promoting deposition of genomic data in existing community data repositories whenever possible.







# **DSAR Policy –data types**



- Phenotype data (associated with genotype data)
  - Demographic information
  - Anthropometric data
  - Disease and health related phenotype data
- Genetic Variation data human & pathogen
  - Sequencing data (whole genome, exome, targeted)
    - Primary data following QC
    - Variant calls following QC
  - Genotype data from arrays
    - Primary array data following QC
    - Variant calls following QC
- Microbiome sequence data
  - Patient/sample phenotypes
  - Non-human 16S rRNA sequence data for microbiome
  - Non-human full genome sequence data for







## **DBAC Guidelines**



- 8 members unrelated to H3Africa consortium
  - Scientists with relevant research experience
  - Biobanking expertise
  - Data expert
  - Ethics expert
  - Legal representative
  - community representative, advocacy group or nurse
  - Ex officio H3Africa members
- Quorum is 5/8 members
- Appointed for 3 years + 3 extra possible
- 3 should stay on with any change in committee







# Microbiome/non-human data



- EGA takes human genotypes and phenotypes
- For non-human data sequences should be submitted to European nucleotide archive (ENA) –open access
- EGA can still store phenotypes (controlled access) and link these to sequences in ENA
- Timelines and process is same as for other data







## Questions



