

# Data Sharing, Access and Release Working Group Meeting

Friday, May 17, 2013, 2:30-4:00 PM

## Working Group Chairs:

Nicola Mulder, University of Cape Town, R.S.A.

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

## Discussion Facilitators:

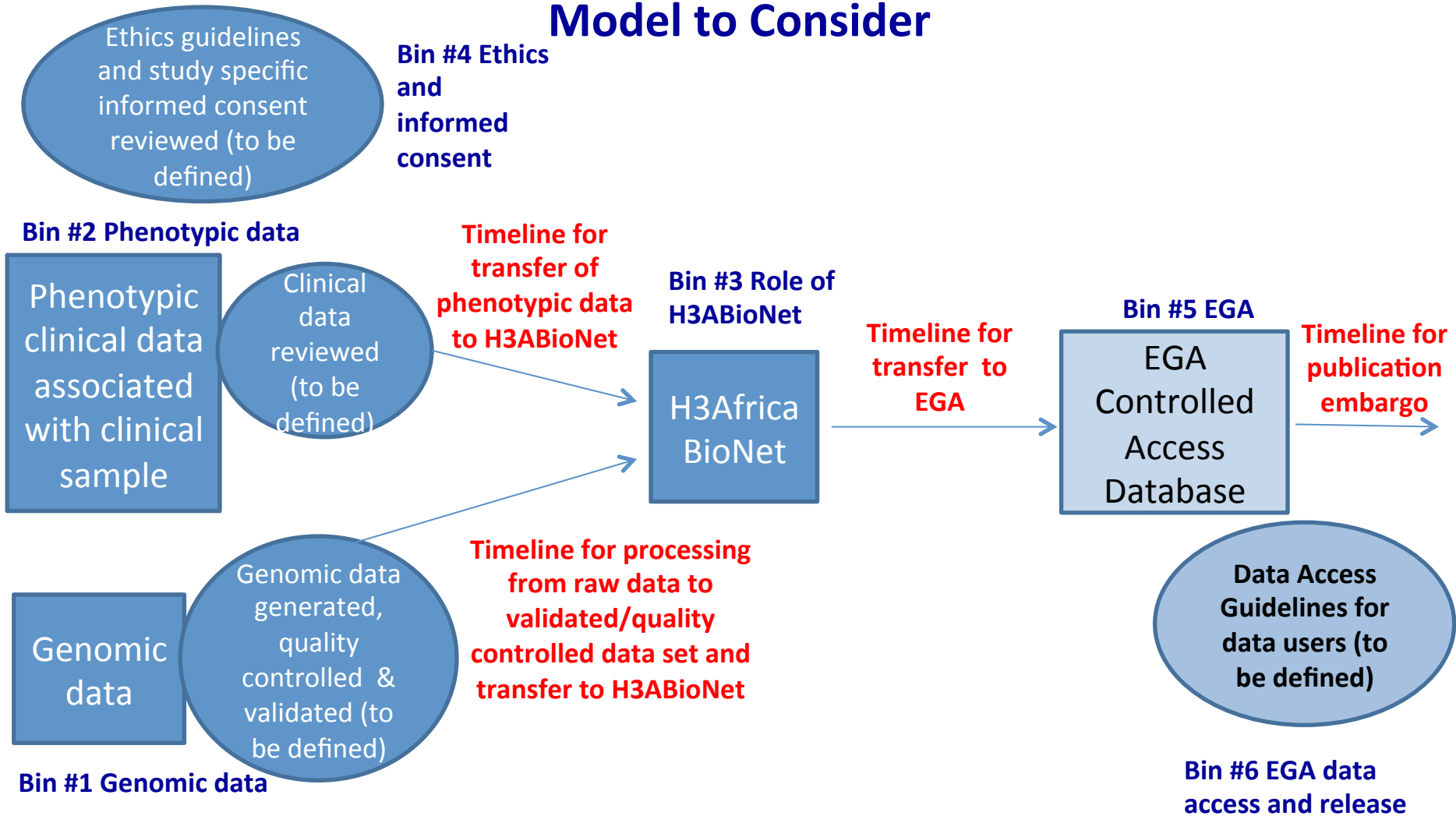
Oduola Ayoade, University of Ibadan, Nigeria

Rex Chisholm, Northwestern University, U.S.A.



# H3Africa Data Sharing, Access and Release Guidelines

## Model to Consider



Protection of the rights and privacy of human subjects

# H3Africa Data Sharing, Access and Release Guidelines

Ethics guidelines and study specific informed consent reviewed (to be defined)

Bin #4 Ethics and informed consent

1. Data types generated and shared
2. Data file formats to be archived and stored at project site, H3ABioNet and EGA
3. Guidelines needed for defining quality control and validation of each data type
4. Guidelines needed for the delineation of responsibilities

Bin #2 Phenotypic data

Phenotypic clinical data associated with clinical sample

Clinical data reviewed (to be defined)

Timeline for transfer of phenotypic data to H3ABioNet

H3ABioNet

H3Africa BioNet

Timeline for transfer to EGA

Bin #5 EGA

EGA Controlled Access Database

Timeline for publication embargo

Genomic data

Genomic data generated, quality controlled & validated (to be defined)

Bin #1 Genomic data

Timeline for processing from raw data to validated/quality controlled data set and transfer to H3ABioNet

Data Access Guidelines for data users (to be defined)

Bin #6 EGA data access and release

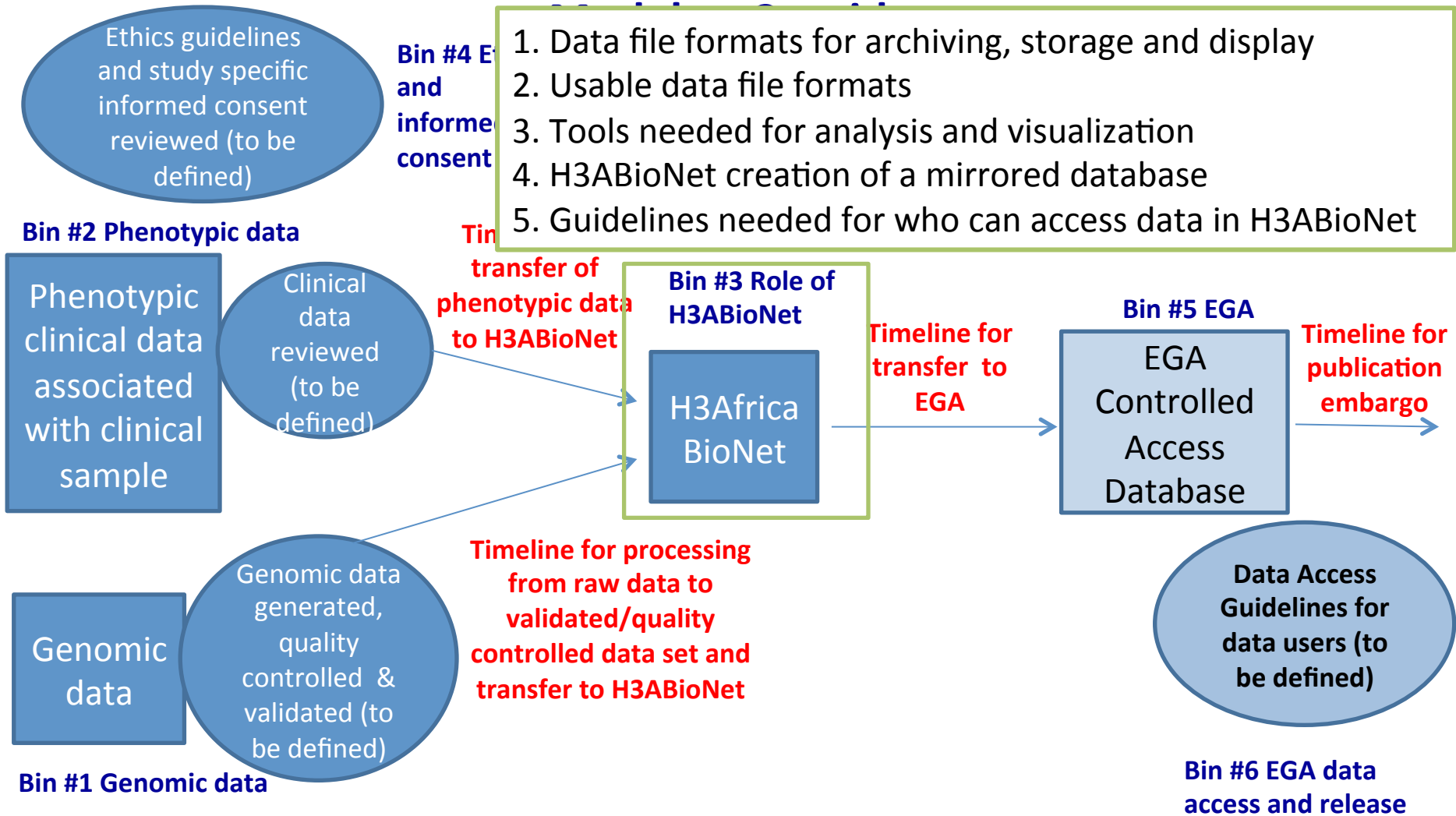
Protection of the rights and privacy of human subjects

# Data Sharing, Access and Release Guidelines

## Bin #1 Genomic Data

1. Data types generated and shared
2. Data file formats to be archived and stored at project site, H3ABioNet and EGA
  - H3A Consortium members will discuss data transfer processes with H3ABioNet
3. Guidelines needed for defining quality control and validation of each data type
  - **Action Item:** H3ABioNet and our WG will discuss with experts regarding a reasonable timeline needed to conduct QC/validation of different types of genomic data and develop guidelines for minimal QC/validation
  - Note: QC/validation is also dependent on how the downstream data analysis, i.e. meta-analysis across the H3A Consortium
4. Guidelines needed for the delineation of responsibilities
  - Dependent upon the experience and needs of the individual research groups

# H3Africa Data Sharing, Access and Release Guidelines



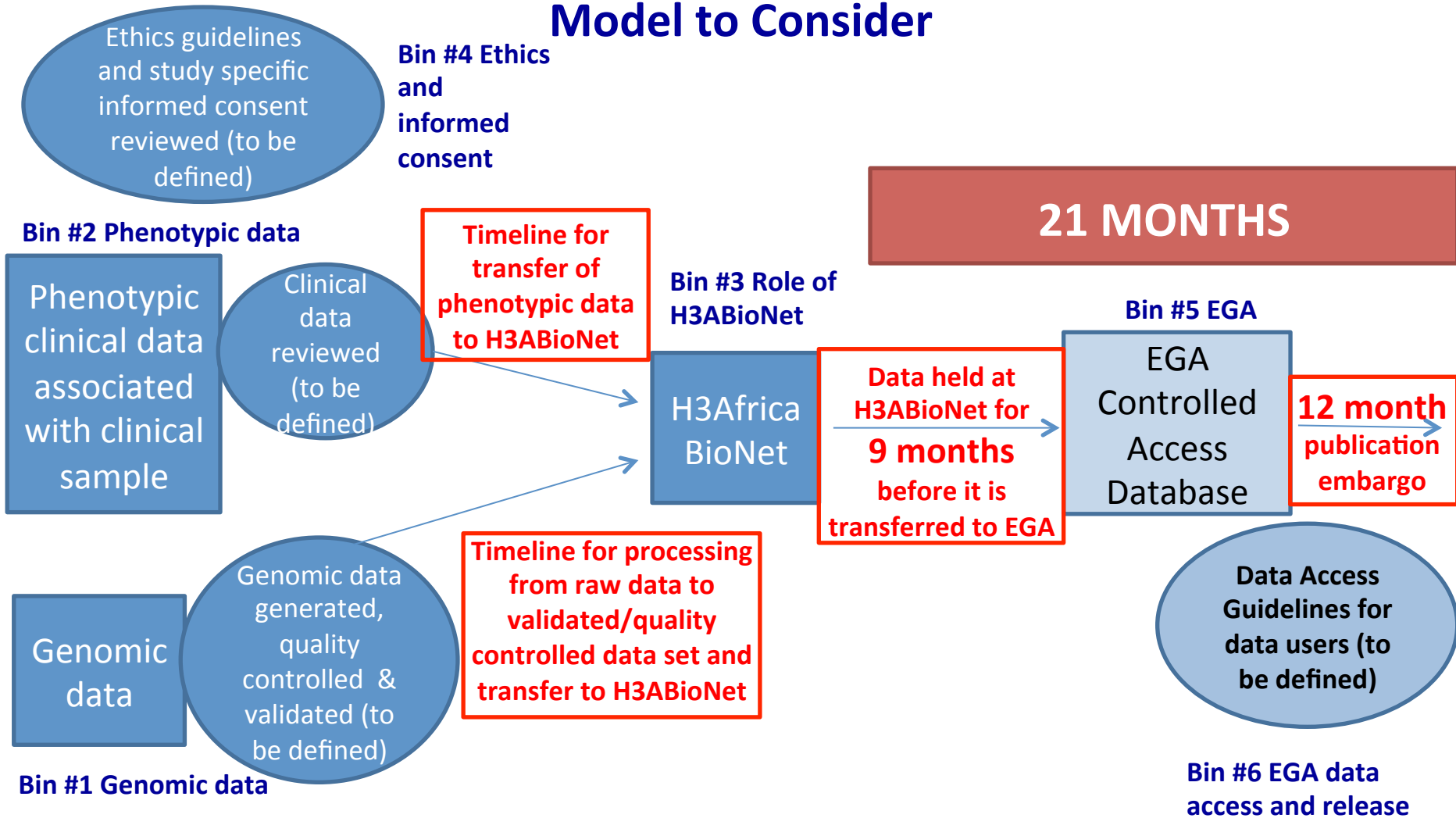
# Data Sharing, Access and Release Guidelines

## Bin #3 Role of H3ABioNet

1. Data file formats for archiving, storage and display
2. Usable data file formats
3. Tools needed for analysis and visualization
  - H3ABioNet can offer bioinformatics training
  - H3A Consortium should begin to assess their bioinformatics needs
4. H3ABioNet creation of a mirrored database
  - H3ABioNet is not intended to be a central repository for all data
  - Raw data files will be stored at H3ABioNet
    - Will act as a backup server
    - Transfer of data to H3ABioNet will act as the time point for when the downstream timelines will begin
5. Guidelines needed for who can access data while staged at H3ABioNet
  - Input is required from the **Ethics and Regulatory Issues WG**

# H3Africa Data Sharing, Access and Release Guidelines

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# Data Sharing, Access and Release Guidelines

## Timelines

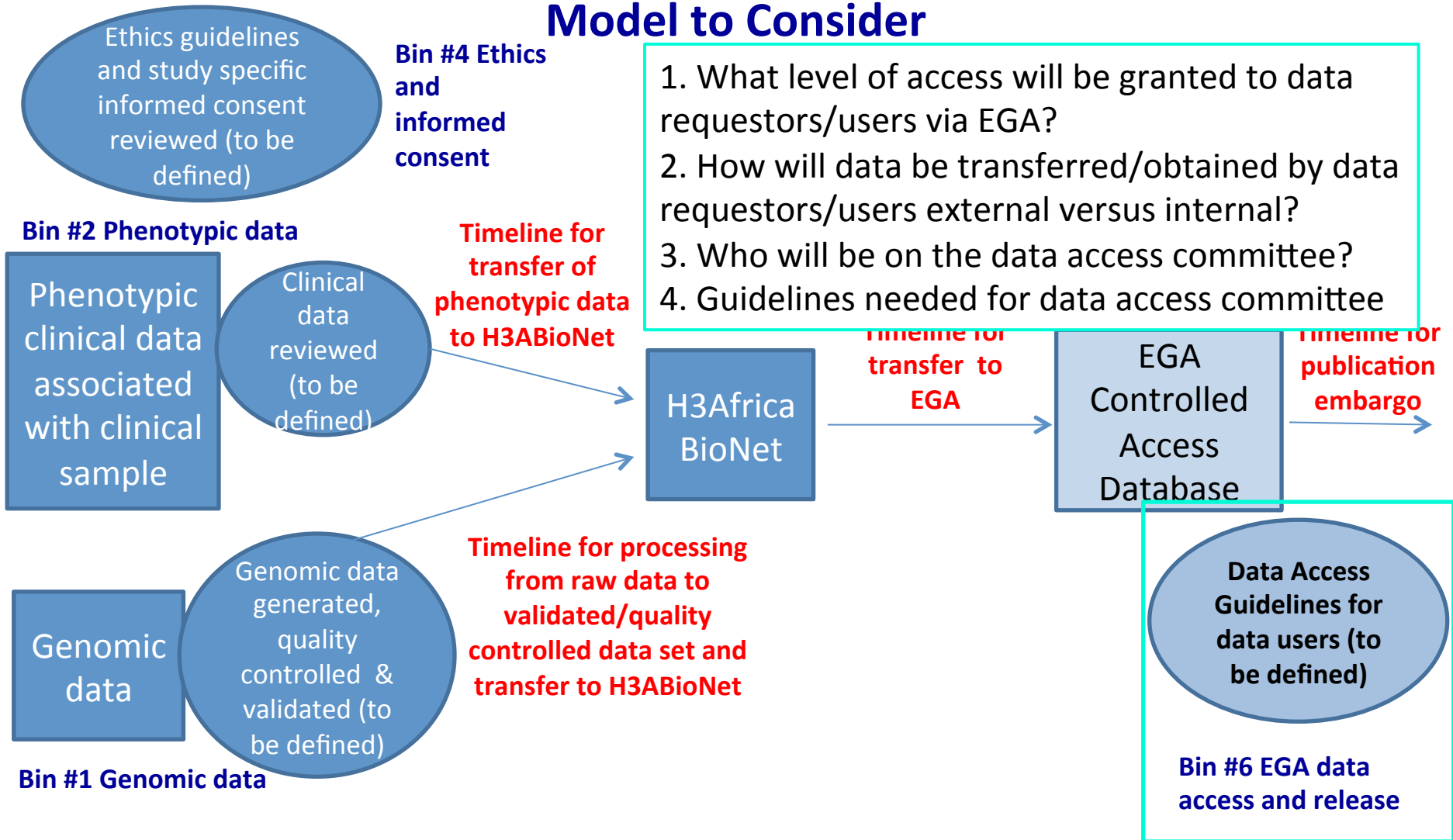
1. Timeline needed for processing raw data to quality controlled and validated data set and transfer of data set to H3ABioNet
  - **Action Item:** H3ABioNet and the WG will discuss with experts regarding a reasonable timeline needed to conduct QC/validation of different types of genomic data and develop guidelines for minimal QC/validation.
2. Timeline needed to transfer phenotypic data to H3ABioNet
  - Needs input from **Phenotype Harmonization WG**
  - Anticipated that phenotypic data will be transferred with the genomic data
3. Timeline needed for how long data will be held at H3ABioNet before submitting to EGA
  - Batch data submission into H3ABioNet, project by project basis
  - Rough timeline: 9 months from the last batch of data submission into H3ABioNet
4. Timeline needed for publication embargo
  - Rough timeline: 12 months

**Action Item: NIH and WT will further discuss the specific timelines and create a proposal that will be shared and discussed with the Steering Committee.**



# H3Africa Data Sharing, Access and Release Guidelines

## Model to Consider



1. What level of access will be granted to data requestors/users via EGA?
2. How will data be transferred/obtained by data requestors/users external versus internal?
3. Who will be on the data access committee?
4. Guidelines needed for data access committee

Protection of the rights and privacy of human subjects

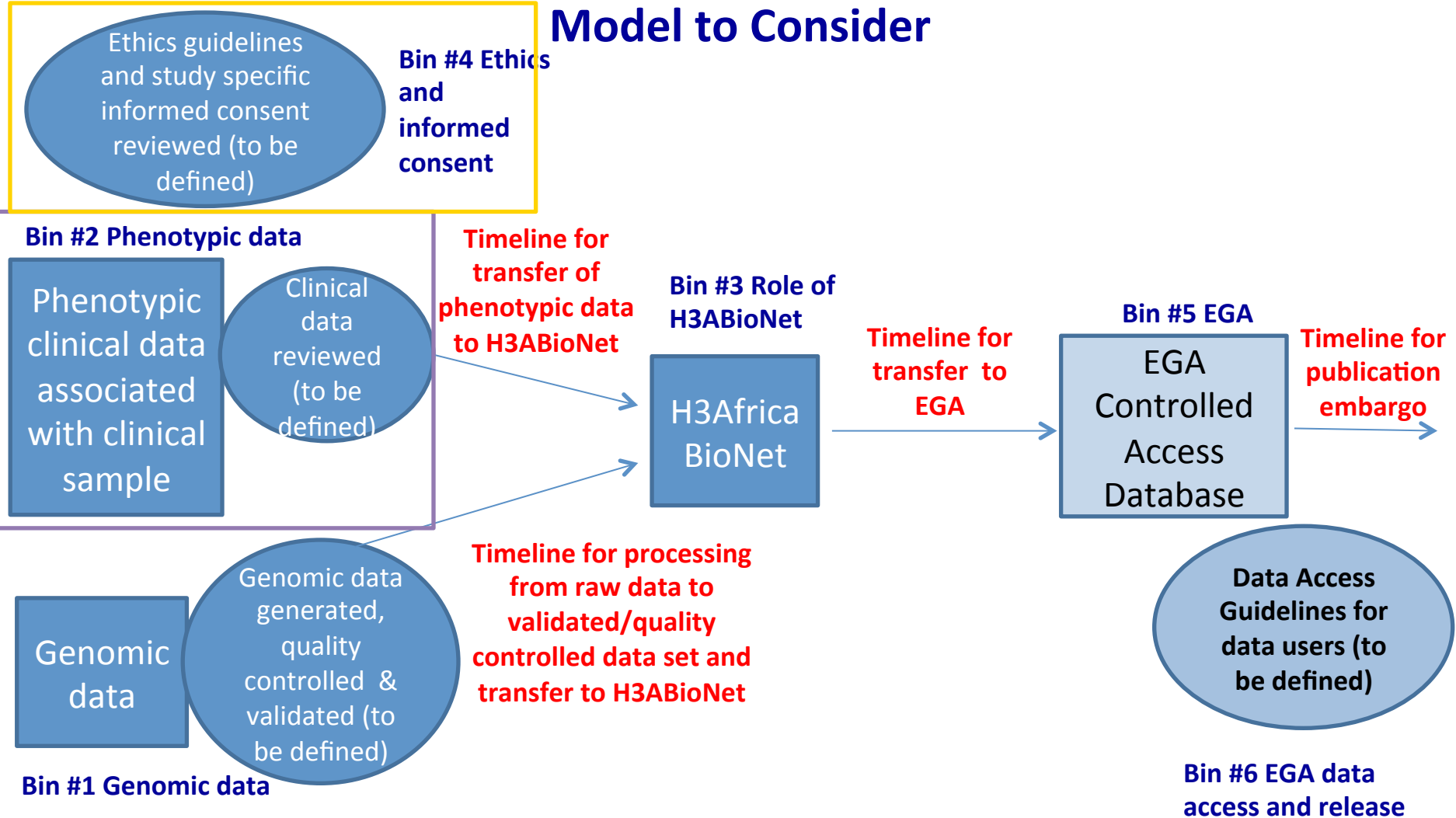
# Data Sharing, Access and Release Guidelines

## Bin #6 EGA Data Access and Release

1. What level of access will be granted to data requestors/users via EGA?
2. How will data be transferred/obtained by data requestors/users external versus internal?
3. Who will be on the data access committee?
  - DAC will be an independent access committee for the entire H3A Consortium
4. Guidelines needed for data access committee
  - Guiding principles need to be agreed upon across the H3A Consortium
  - **Action Item**: Our WG will develop guidelines and share with the Steering Committee for discussion and approval.

# H3Africa Data Sharing, Access and Release Guidelines

## Model to Consider



Protection of the rights and privacy of human subjects

# Interactions with Other Working Groups

**Ethics and  
Regulatory  
Issues WG**

**Data Sharing,  
Access and  
Release WG**

**Phenotype  
Harmonization  
WG**

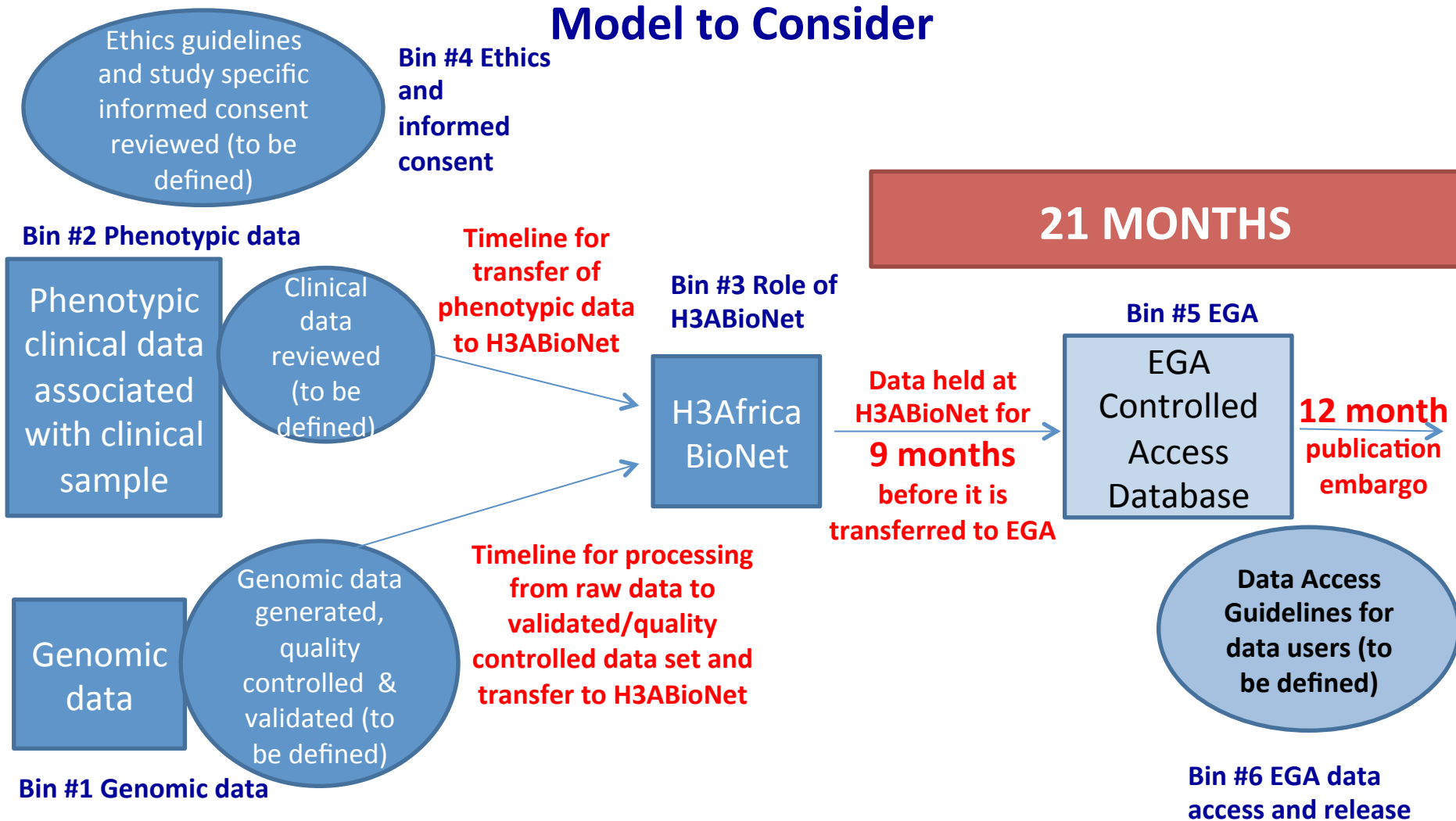
1. Guidelines needed for reviewing informed consent documents for data storage, access and release
2. Who reviews informed consent documents and ensures that they are in line with data, access and release guidelines?
3. Who can access the data while it is staged at H3ABioNet?
4. What level of access will Consortium have to the Consortium generated data?
5. What genomic and phenotypic data will be available for access at EGA?
6. Consent form language for the meta-analysis of data across the H3A Consortium

1. Data standards and data file formats
2. Agreement on which phenotypes to be captured and shared
3. Guidelines needed for archiving and storing data
4. Guidelines and timelines needed for sharing, access and release of phenotypic data

**Protection of the rights and  
privacy of human subjects**

# H3Africa Data Sharing, Access and Release Guidelines

## Model to Consider



Protection of the rights and privacy of human subjects

# Next Steps

- H3ABioNet and the WG will discuss with experts regarding a reasonable timeline needed to conduct QC/validation of different types of genomic data and develop guidelines for minimal QC/validation.
- Our WG will develop guidelines for the data access committee and share with the Steering Committee for discussion and approval.
- NIH and WT will further discuss the specific timelines and create a proposal that will be shared and discussed with the Steering Committee.
- Our WG will continue interacting and discussing with the other members of the H3A Consortium, specifically the Ethics and Regulatory Issues WG and Phenotype Harmonization WG.



# Data Sharing, Access and Release Working Group Members



## **Abayomi Affiliated**

Akin Abayomi  
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Catherine Rossouw

## **Abimiku Affiliated**

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## **Ramsay and Sankoh Affiliated**

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