HuBMAP Consent Policy 07/25/2019

1. Sequence level data will be open access on HuBMAP portals only with consent of subject or legally authorized representative. Open access is defined for the Consortium as behind a click-off data user agreement. The consent must contain the following elements.

a. genomic and phenotypic data will be generated and may be used for future research (on any topic).
b. before submission to NIH/federal repository, data will be stripped of identifiers. Safeguards to protect the data will be implemented.
c. access to genomic and de-identified data will be explicitly consented to allow open access and use of data for any purpose.
d. even if data security measures are implemented, there are risks that cannot be foreseen.
e. no direct benefits to participants are expected for any secondary research that may be conducted.

2. Sequence level data generated from subjects enrolled with consents missing any of the elements 1a through 1e (e.g. unrestricted consents without explicit mention of GDS) will be placed under restricted access (i.e. dbGaP or equivalent).

3. Investigators are free to disseminate sequence level data they have generated as they see fit consistent with the regulations and oversight of their individual institutions. However, sequence level data will not be available open access on HuBMAP portals unless #1 is met.

4. Non-sequence level data will be open access. These components include subject metadata, which will be stripped of any identifying features.