Genomic Data Sharing Sensitivity Determination Guidance and Checklist

Effective November 1, 2018, the NIH Office of Science Policy released an update to the NIH Genomic Data Sharing Policy to allow unrestricted access to genomic summary results (GSR) unless the study population is deemed sensitive in which case GSR results will be maintained in controlled access.

GSR are defined as:
"results from primary analyses of genomic research that convey information relevant to genomic associations with traits or diseases across datasets rather than data specific to any one individual research participant (e.g., genotype counts and frequencies; allele counts and frequencies; effect size estimates and standard errors; likelihoods; and p-values)."

Sensitive study populations are considered those that may have heightened privacy risks or have other restrictions on the use of the data, e.g. populations from isolated geographic regions, affected with rare or potentially stigmatizing traits and/or diseases, or populations with data restrictions.

CCR has created the following checklist to help ascertain whether a study population might be considered sensitive and GSR should be maintained in the controlled access environment.

PI Name:_____ **Study Number:**_____

Study Name: _____

Is your study population:	**Yes**	**No**
from an isolated geographic region?	◯	◯
affected with a rare trait or disease?	◯	◯
affected with a potentially stigmatizing trait or disease?	◯	◯
is the study population small enough that a study participants privacy could be at risk?	◯	◯
is the study population Native American/Alaskan Native or other indigenous populations which may have tribal laws that restrict the use of data?	◯	◯

If YES to any of the above questions, your study population may be considered sensitive.

Investigator Recommended Sensitivity Determination:

◯ Sensitive ◯ Not Sensitive

CCR AdHoc Committee Sensitivity Determination:

◯ Sensitive ◯ Not Sensitive Date:_____