

NIH Genomic Data Sharing Policy - Individual Level Data vs. Genomic Summary Results

Last updated: 2/14/19

On the [Institutional Certification](#) form required as part of NIH Genomic Data Sharing Policy, there are two sections regarding access to data that need clarification – individual level data and genomic summary results.

Individual Level Data:

Below is a screenshot of the question regarding individual-level data from the Institutional Certification form.

The individual-level data are to be made available through (check one)

- controlled-access**³
- unrestricted access**⁴

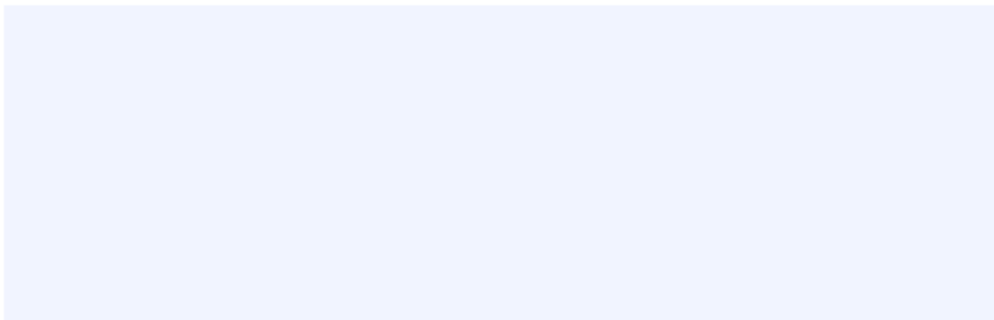
“Controlled-access” will almost always be checked here. “Individual data” in this question includes data such as genome-wide association studies (GWAS), whole exome data, and sequencing data. Marking “unrestricted-access” would allow these data to be publicly accessible; no application would be needed and they could be posted anywhere. “Controlled-access” restricts access to investigators that have submitted an application and are approved for use of the data. The specific data use limitation can be denoted on page 3 of the Institutional Certification form.

Genomic Summary Results:

Below is a screenshot from the Genomic Summary Results section of the Institutional Certification form.

The genomic summary results (GSR) from this study are only to be made available through
 controlled-access.

Explanation if controlled-access was selected for GSR.



In light of a recent NIH Policy ([NOT-OD-19-023](#)) that now allows unrestricted access for genomic summary results (GSR), we are highly encouraging sites to NOT select this checkbox. By not

selecting, you are choosing to have summary statistics shared more broadly. This includes data such as p-values, allele frequencies, and odds ratios. If your dataset(s) includes data from a “sensitive” group (such as those with rare or potentially stigmatizing traits), you may select “controlled-access” and provide a brief explanation of why these data are sensitive in the box below.